An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

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Abstract

Background: In the United Kingdom (UK) the number of males with Eating Disorders (ED) admitted to hospital has risen by 70% since 2000. Taking account of under-reporting and misdiagnosis, men are now thought to represent 25% of those diagnosed with anorexia. To date, within academic literature, there has been a strong focus on EDs in women, perpetuating and maintaining stereotypical ideas of anorexia and the existent social stigma. Whilst there has been a plethora of quantitative studies regarding anorexia per se, with some specifically relating to men, there is a dearth of qualitative studies, with only two studies examining the experiences of men with EDs accessing services identified within the literature review. In adding to such a limited body of knowledge, this study was undertaken with the purpose of exploring the lived experiences of men who had an ED, namely anorexia, and/or an eating disorder not otherwise specified.

Methodology: Qualitative research, adopting a narrative approach was used, in order to promote the hearing of the participants’ own constructed stories. Data was collected via narrative interviews with seven men aged 23-34 years old. In the first instance narrative analysis was used for each man’s story, with thematic analysis being used to explore commonalities and difference across all seven interviews.

Findings: The interviews highlighted the need for male stories of anorexia to be researched and voiced. The men shared many background similarities, experiencing a range of negative consequences during their everyday living; from discriminatory health care, to problems with employment and isolation. Four major themes emerged from the cross-narrative analysis: (1) The final John Doe, (2) Masculinity – The beast in me; (3) Not working 9-5; and (4) Help, I need somebody – Bedlam revisited.

Conclusions: If men experiencing eating disorders are to receive appropriate and supportive health care, further research is needed to ensure better understanding and acceptance on the part of society, service providers and employers.
CHAPTER 1 - SETTING THE SCENE

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1.1 – INTRODUCTION

Within the United Kingdom (UK) the admission to hospital of males with Eating Disorders (ED) has been reported to have risen by 66% since the year 2000 (Knowles, 2011) and 70% since 2011 (Marsh, 2017). EDs fall under the diagnostic auspices of a mental illness and are listed in the Diagnostic and Statistical Manual (DSM) -5 (American Psychiatric Association, 2013). In the early 1990s it was suggested that only approximately 10% of people with EDs were male (Wolf, 1991). However, towards the end of the 1990s, and at the turn of the millennium, the number of cases of males with an ED was much greater (Braun et al., 1999; Brown, 2007). In a more recent study conducted in the United States involving approximately 3,000 people from the general population, it was found that 25% of those who had experienced an ED were male (Hudson et al., 2007). This figure was reiterated by Skolnick (2014) who believes males can make up as much as 25% of the anorexic population because of under-reporting and misdiagnosis. Räisänen and Hunt (2014) suggested:

Men with EDs are under-diagnosed, undertreated and under-researched. In particular, there is a lack of qualitative research on men’s experiences of EDs and a continuing perception of EDs as a ‘female illness’. (p. 6)

It has been suggested that men and women who are diagnosed with an ED share similarities in many aspects of the illness (Cooperman, 2000), but Carotti et al. (2008) concluded that males experiencing anorexia tend to have gender identity problems, higher impulsiveness and a lower sexual drive than their female counterparts. Likewise, it has been suggested that recent research has focused on the assumption that EDs in men are associated with homosexuality (Jones and Morgan, 2010). However, regardless of similarities and differences, EDs in men are now more readily acknowledged, though the social and cultural stigma attached to men diagnosed with the illness remains a barrier to treatment (Paterson, 2004; Soban, 2006; Brown, 2007; MacCaughelty et al., 2016).

To date, within academic literature, there has been a strong focus on EDs in women, whilst men have been almost completely ignored (King, 2013), helping to perpetuate and maintain the existent stigma. Stigma with regard to EDs, mental illness and male illness in general, can be problematic as it has the potential to compromise masculinity (Courténay, 2000). Mental illness per se attracts stigma, and reducing such stigma involves raising...
public awareness and understanding by bringing the stories of those diagnosed with mental illness to the fore (Morris, 2006). In a review of the literature, Jones and Morgan (2010) examined 77 research studies on the subject of male EDs, and concluded that not one of the studies explored what it was like to be a man living with an ED. Exploring the subjectiveness and distress men experience is considered an important area for critical sociological research, particularly in relation to the meanings they give to, how they cope with, or seek help for distress (Ridge et al., 2010). As EDs can be life threatening, with mortality rates higher than any other psychiatric disorder (Klump, et al., 2009), it has been suggested that in addition to raising awareness regarding this problem existing for men as well as women, services need to be particularly sensitive to men who may be reluctant to seek help (Tyler, 2013).

In light of the above, the intention of this study was to add to the limited body of knowledge regarding the lived experiences of men with EDs and, in the telling of their stories, it was anticipated that this would be a step towards increasing knowledge and understanding and developing a framework for reducing stigma. However, no research can be undertaken without looking at previous research and theory pertaining to the area of study. In this case, areas that are examined within the introduction to provide background and context to the study include; personal reasons for undertaking the study, the medical classification of EDs, as well as a brief examination of the theoretical framework, examining the relationships between cultural and social capital, masculinity, media portrayals and mental health stigma.

1.2 – PERSONAL EXPERIENCES OF ANOREXIA: A REFLECTIVE STUDY CONTEXT

At this point, it is important to state that I have experienced an eating disorder. I believe that this is an important section within my thesis, as it provides context to why I chose this topic and an understanding as to some of the reasons behind the research methodology chosen.

I am a male in my early 40s and since my late teens and early twenties I have battled on and off with various patterns of ED behaviour. This culminated with me, at the age of 28, being diagnosed incorrectly with an eating disorder not otherwise specified (EDNOS),
which was later treated as ‘purging anorexia’, yet still my classification was EDNOS. As with many men I faced a number of problems in being categorised I had no idea as to the seriousness of the disorder and was unable to get help when I needed it most. This resulted in a belief that my illness was not serious, if it was I would be getting treatment. I therefore continued to work and my physical health declined. More worryingly was the decline I experienced in my psychological health and I was soon unable to continue in my career as a teacher.

After coping for a number of years privately (although my family could see I had problems, but did not know how to help) I sought medical help and was informed that the waiting list to see a NHS ED Specialist could take approximately 12 months because my body mass index (BMI) reading was not classified as urgent. Consequently, on the advice of my G.P., I saw a private specialist, who informed me that whilst I needed treatment straight away, as I did not have medical insurance I would not be able to afford the treatment and would therefore have to wait for an appointment with the NHS. When I was able to see the NHS ED Service, I was informed that despite losing over 15% of my original body weight, due to my BMI I was still not able to get help. Subsequently, I did get help from the ED services after being admitted to a psychiatric hospital for self-harm. On admission my blood was tested and found to be dangerously low in certain minerals, thus prompting the beginning of five years of CBT and Family Therapy.

Whilst still working as a teacher one of the first things I did was to inform my line manager of my medical issues. His response was; 1) not to know how to respond 2) to suggest, “could we not mention it again” and 3) it would be best not to mention this to the school’s senior staff as having a “mental illness” would count against me for promotion. This response is perhaps more common than people may think, Jaffe’s (1997) account of a friend of a U.S Senator who warned him against publicly discussing his diagnosis of prostate cancer, arguing that “some men might see (his) willingness to go public with his private struggle as a sign of weakness” (p. 134).

My own health continued to suffer, and I became more and more isolated which was a mixture of turning inwards and my friends/colleague shunning me due to their lack of comfort/understanding with my illness. My family were bombarded with questions from people asking if I had cancer, and when my parents responded by saying I was suffering
from an ED they would be met with the response of “we didn’t know men can get eating disorders”. For example, my mother was stopped one day by the till operator in a supermarket, asking was she the mother of the man with anorexia. My mother told the operator she was, for the operator to exclaim that she “didn’t believe men could get eating disorders” which was then reinforced by the women next in the queue who had overheard the conversation.

With many more experiences like those presented above perhaps it is no surprise that I wish to advance the understanding for men with EDs, as at almost every turn my family and I have been met with ignorance and a rigid healthcare system. I therefore believe that there is a need to actively explore how EDs impact on all aspects of the lives of men and, in the long term, develop guidance for the benefit of stakeholders/care providers.

### 1.3 – MEDICAL CLASSIFICATION OF EATING DISORDERS

Eating Disorders cover a wide spectrum of mental illnesses. For the purpose of this study men with anorexia and men with anorexic symptoms, but classified as Eating Disorder Not Otherwise Specified (EDNOS) or a-typical anorexia will be the focus of the study. For clarity, the next section of this introduction will offer the rationale for why these two types of EDs were chosen.

The APA periodically reviews the classification of mental illnesses and their classifications are used by the medical profession worldwide, including the UK. A new set of guidelines, DSM-5, was published in 2013, replacing the previous DSM-4 last updated in 2000, with this study overlapping both DSM-4 and 5. The publication of the DSM-5 was, in theory, a welcome improvement in the ED community, as previous classifications were highly criticised due to the limitations inherent in the guidelines (Freeman, 2005). DSM-4 (American Psychiatric Association 2000) listed three types of EDs, with further details of the criteria for anorexia being offered in Figure 1 (next page). The three types of eating disorder were, anorexia, bulimia and EDNOS.
Figure 1 - DSM-4 Anorexia Classification (American Psychiatric Association 2000)

1. Refusal to maintain body weight at or above a minimally normal weight for age and height (e.g., weight loss leading to maintenance of body weight less than 85% of that expected; or failure to make expected weight gain during period of growth, leading to body weight less than 85% of that expected).
2. Intense fear of gaining weight or becoming fat, even though underweight.
3. Disturbance in the way in which one’s body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.
4. In post-menarcheal females, amenorrhea, i.e., the absence of at least three consecutive menstrual cycles. (A woman is considered to have amenorrhea if her periods occur only following hormone, e.g., oestrogen administration.)

Specify type:

- Restricting Type:
  - during the current episode of anorexia nervosa, the person has not regularly engaged in binge eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas)

- Binge-Eating/Purging Type:
  - during the current episode of anorexia nervosa, the person has regularly engaged in binge eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas)

A person who did not fit into the rigid classification of anorexia or bulimia were classified as having an EDNOS. The DSM-4 classification of anorexia (See Figure 1 previously) made it difficult for a man to be classified with anorexia as Criteria D referring to amenorrhea was extremely confusing, leading some people to believe men could not experience anorexia. Freeman (2005) suggested, “As per this diagnostic indicator, males should be excluded from this disorder” (p. 63). This strictly speaking was not the case, as men were diagnosed as being anorexic, but the problem of amenorrhea has been a bone
of contention as there is no like for like comparison for men, with male sexual functioning not being easily comparable with weight loss as is the case with women.

Another factor making it difficult for men to be diagnosed with anorexia, was that they had to have a body weight 15% less than their “expected” weight. This kind of judgement was, and is, problematic due to a number of issues: Firstly, the commonly accepted way in which the healthcare sector calculates ideal weight is through the use of BMI. BMI is a calculation derived from height and weight and does not take into account bone structure or muscle mass. In addition, BMI is not a specific figure, but rather four classifications; underweight, normal, overweight and obese. For example, a 6ft male is classed as having a healthy normal BMI at a weight between 9st 9lbs (63.5kg) and 12st 8lbs (81.6). The calculation of 15% of expected weight is open to interpretation. Is that 15% of 9st 9lbs (8st 5llbs) or the highest or mid figure in the range? Schneider et al. (2010) found that BMI is not the best indicator of obesity or for weight loss, while Treasure et al. (2009) suggest BMI should only be used as a “rough estimate of medical risk” (p. 43). The National Institute for Clinical Excellence (NICE) (2004) guidelines stated;

In anorexia nervosa, although weight and BMI are important indicators they should not be considered the sole indicators of physical risk (as they are unreliable in adults and especially in children) (p. 10).

Secondly, Jones and Morgan, (2010) suggested men with EDs tend to focus on low body fat, muscle, strength and exercise rather than low weight, which further complicates using an arbitrary figure for diagnosis. Others have made similar conclusions, stating women are dissatisfied by body fat, whereas men concentrate on muscle dissatisfaction or fat to muscle ratios (Mitchison and Mond, 2015). Thirdly, men with anorexic symptoms have been found to actually be overweight when they first become ill (Cooperman, 2000; Strober et al., 2001; Fernández-Aranda et al., 2004; Freeman, 2005, Raevuori et al., 2008; Raevuori et al., 2009 and Gueguen et al., 2012). Cooperman (2000) suggested men with anorexia tend to be 15% over ideal body weight before becoming ill, as opposed to women who tend to be 10% below their ideal body weight. The implication of this is that men have to lose more weight before being diagnosed with anorexia leading to a longer period of illness before treatment is available, perhaps resulting in greater difficulty in addressing psychological issues.
With the advent of the DSM-5 (APA, 2013) some of the major issues relating to the diagnosis of EDs have been clarified (See Figure 2 on the following page for the criteria for anorexia). The current guidelines (DSM-5, 2013) have expanded the number of eating disorders to, pica, rumination disorder, avoidant/restrictive food intake disorder, anorexia nervosa, bulimia nervosa, binge eating disorder, feeding or eating disorder not elsewhere classified.

**Figure 2 - DSM-5 Anorexia Classification (American Psychiatric Association 2013)**

1. Restriction of energy intake relative to requirements leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health. Significantly low weight is defined as a weight that is less than minimally normal, or, for children and adolescents, less than that minimally expected.
2. Intense fear of gaining weight or becoming fat, or persistent behaviour that interferes with weight gain, even though at a significantly low weight.
3. Disturbance in the way in which one’s body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.

Specify current subtype:
- **Restricting Type:**
  - during the last 3 months, the individual has not engaged in recurrent episodes of binge eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas).
- **Binge-Eating/Purging Type:**
  - during the last 3 months, the individual has engaged in recurrent episodes of binge eating or purging behaviour (i.e., self-induced vomiting or the misuse of laxatives, diuretics, or enemas).

The classification of new EDs allows people who previously fell into EDNOS to be better diagnosed and treated. The removal of amenorrhoea as a factor for classification in DSM-5 is perhaps the most significant, and for men, empowering change, as it removes gender bias. Attia and Roberto (2009) contend that amenorrhoea is not a relevant feature in
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several sub-groups of individuals, including men, who exhibit other features of anorexia and therefore it should not be a factor used to classify the illness. The removal of amenorrhoea as a classifying symptom also enables women to be diagnosed with anorexia, without the loss of menstruation, increasing their chances of getting appropriate treatment earlier (Attia and Roberto, 2009). The DSM-5 (2013) also removed the criteria for losing 15% of ‘expected’ body weight and although the wording in the definition is vague, it is anticipated this will be better than what was previously stated.

Due to the difficulties of diagnosis, I have decided to focus my study on men with a diagnosis of anorexia or EDNOS who have experienced anorexic symptoms, as a man could have been diagnosed with EDNOS in the era of DSM-4. This not only increases the number of potential participants, but it will also allow the exploration of the life stories of men who have the potential additional barrier of being unable to be classified with the illness, for all intents and purposes, they suffer from. It is also important to include men diagnosed with EDNOS, as the DSM-5 (2013) guidelines simplify the criteria for diagnosing anorexia, meaning men in similar circumstances, in theory, will be diagnosed with anorexia rather than EDNOS. However, this assumption has been challenged, the suggestion being that whilst DSM-5 has allowed women with EDNOS to be more easily classified, it has not translated to men (Compte et al., 2015).

1.4 – THEORETICAL FRAMEWORK

1.4.1 - CAPITAL

Connell (1995) suggested that masculinity is created by the process of socialisation, and it can therefore be changed through the same processes. From a non-positivist viewpoint, and in sociological terms, this refers to personal growth through day to day interactions, decisions, needs and wants, often described as ‘Social and Cultural Capital’. This growth is influenced by whom and what we come into contact with, from family and friends to media. Social and Cultural Capital in essence describes the assets we gain (personal growth) through various non-financial interactions. The concept of Capital was originally created by Bourdieu and Passeron (1973) to examine educational underachievement.
Bourdieu (1986) later refined his and Passeron’s work, identifying four forms of Capital, these being:

1. Cultural (social aspects of a person)
2. Economic, (command of cash financial assets),
3. Social (group membership, relationships), cultural knowledge, education, lessons learnt from others, advantages a person has.
4. Symbolic (resources available to an individual on the basis of honour, prestige or recognition).

Symbolic Capital can clearly be seen within EDs on Pro-anorexia websites which promote unhealthy behaviour, having the potential to make people more entrenched in the illness. Bourdieu (1986) further wrote that each form of Capital can be broken down further into:

- Embodied Cultural Capital, consisting of acquired, and passively inherited, properties (such as behaviours) which are not genetic (nature) but nurtured over time.
- Objectified Cultural Capital, consisting of physical objects that are owned, such as scientific instruments or works of art.
- Institutionalized Cultural Capital, consisting of institutional recognition, most often in the form of academic credentials and/or qualifications.

Bourdieu’s (1986) concepts have been used to examine how our experiences in life help to create the person we are. We are constantly surrounded by information and, taking this on-board, we consistently build and refine our belief and moral systems. It is therefore unsurprising that the media, often criticised for its ED reporting, plays a major role in the dissemination of such information and is seen as being an important influence in the creation and evolution of a person’s social and cultural capital.

1.4.1.1 - Spreading Capital - The Media

Media is an all-encompassing term, relating to the various channels of communication where information is relayed. This can be in many different forms and can be both direct and indirect. Whatever the medium, media is a transmitter of ideas, opinions and trends, and as a result, capital can flow much more quickly. “The popular media have long been considered to have an important role in defining and shaping American Culture” (Craig,
1992, p. 3). However, the role of media as a creator of capital is extremely unclear and ambiguous, and it depends upon many things such as the framing of the message, the audience and the medium used. Evidence of this was established by Philo (1995) who found public perceptions of the 1980s U.K. miners’ strike to be heavily influenced by the position taken by the media that they had access too.

Early Marxist theories of the media being a tool of domination by the elite (Haralambos & Holborn, 2008), have somewhat mellowed, although other schools of thought, such as the Frankfurt school, and evidence such as the workings of commercial T.V., provide ammunition to these arguments. MacNamara (2003) suggested whilst media may not tell people “what to think” it does set the agenda of “what they think about”. This was reinforced by Murphy et al., (2013). With regard to this study, the power of external stimuli is demonstrated by men exposed to advertising which uses muscular male figures, immediately having feelings of body dissatisfaction (Leit et al., 2001).

Any proposal to examine the media’s influence on capital must examine how the media communicates. Current academic thinking generally follows Hall’s (1999) (Marxist leaning) theories (originally from 1973) on encoding and decoding, and questioning the linear nature of mass communication theories based around sender-message-receiver. Hall argued that the meanings inherent in a message are coded by the sender (encoder), and then the receiver (decoder) will interpret the message. The same message can and will be interpreted differently dependent upon the receiver’s frame of reference. Hall (1999) suggested that a sender could not fully control how the receiver interpreted (decoded) the message, a point Norris et al. (2003) exemplified with the different interpretations of 9/11, with those responsible being terrorists and murderers to some, and martyrs and freedom fighters to others.

Hall (1999) identified four codes and how they are interpreted in communication: (1) The dominant or hegemonic code which is the code the encoder (sender) expects the decoder (receiver) to recognise and decode. (2) The professional code which replicates the hegemonic code, but from a position of authority such as an expert summariser. (3) The negotiated code, acknowledging the hegemonic definitions, but allows exceptions to the rule. (4) The oppositional code where the decoder determines the code in a different way than intended. The first two of Hall’s (1999) codes reinforce cultural hegemony, and as a
result allows the dominant institutions in society to keep control; this in short helps to dictate the spread of capital. Hall’s theoretical perspective ties in with that of leading masculinity theorist, Rowena Connell, their theories being linked to Gramscian Hegemonic theory.

Hall’s (1999) theories on encoding and decoding can be further explained by examining how messages are encoded or framed. The frame can be defined as how a story is presented in order for it to be received by its target audience. A frame is created through the use of key concepts, stock phrases and images which are used to reinforce common ways of interpreting events (Norris et al., 2003). In short, the use of concepts, phrases and imagery, which are already known through social capital, allow messages to be simplified and concise, as the recipients are already conditioned to their meaning. Messages, therefore, which do not fall into this conditioning may not be picked up, making it hard to alter perceptions (Norris et al., 2003). Over time a new frame can become mainstream, although it is not known why one frame may become mainstream rather than another. However, common sense would suggest that once a frame is repeatedly used in mainstream media, recipients become more conditioned to changing their view. It is clear that over time capital can be changed through the media “Who we are” and “What we want to be” is a phenomenon which the media helps us to construct, through film, photography, editorials, and indirectly through our parents and peers who have a construction of the messages they have seen in the media, which can be controlled and changed by the dominant groupings of that time (Kimmel, 2003).

1.4.1.2 - Media as a Capital Disseminator and Eating Disorders

In the past, the media has been blamed as the creator of EDs, but this has been challenged and shown to be largely incorrect (Stice et al. 2001). Media is now seen to act as a trigger to a person who has a pre-disposition to having an ED (Tyre, 2005). However, Becker et al.’s (2002) study showing the impact of TV in Fiji on body image dissatisfaction offered an indication of the media’s power to influence capital. Other studies (Lee & Lee, 2000; Tong, et al., 2005; Younis & Ali, 2012; Musaiger, et al., 2014) have indicated the spread of western culture has brought increased cases of EDs, with it having greater influence on male adolescents than on their female counterparts (Toro et al., 2005). Studies such as Agliata and Tantleff-Dunn (2004) have shown that media imagery and portrayals of the
ideal male body leads to dissatisfaction in men, showing men have similar worries over image as women. From an ED viewpoint, Cooperman (2000) is one of many to highlight the importance of health promotion. Her study, based around males with EDs, found that a local media article highlighting the existence of male EDs resulted in a rise in referrals of men with EDs in that particular area.

Research has shown that our behaviours, and therefore identity, are in part a result of the society we live in and the result of the various forms of capital we are exposed too. Bourdieu, (2001) demonstrated this within his anthropological studies on Kabyle society, notably the rights of passage of men. In the sphere of EDs and body image, Becker et al., (2002) showed that there was a link between the introduction of T.V. in Fiji and a change in eating behaviour and idealised body image. Tong et al., (2005) argued that Westernisation is a factor in the increase in the number of people with EDs. Likewise, Lee and Lee (2002) found that women’s concerns about body fat became more pronounced the more westernised the city in China they lived in became. However, Abdollahi and Mann’s (2001) conclusions, based on Iranian women living in Iran and the U.S.A. found no correlation between western culture and EDs.

McCabe and McGreevy (2011) found a major influence/factor for men to lose weight were messages in the media, while the main factor for men to put on muscle mass came from their peers, highlighting the importance of socio-cultural influences on adult males’ behaviour in changing their body image. These findings were reiterated by Morgan and Arcelus (2009) who found external influences such as the media and social clubs were important to all men. The media’s portrayal of EDs, whilst improving over time, still has the potential to create a barrier for sufferers (Beat, 2011a; Beat 2011b). Cooperman’s (2000) study indicated that there were still many barriers to overcome particularly for men, the lack of change since Cooperman’s (2000) study is a recurring theme in this thesis.

1.4.2 - MASCULINITY

Connell (1995) was clear when writing that masculinity is created through socialisation. Having established that belief systems are influenced by social and cultural capital, and capital is disseminated through human interactions, (of which media and peer relationships
are two of the most influential) it is important to consider masculinity, its underpinning theories and its impact on men with EDs.

Crosscope-Happel et al. (2000) suggest boys form an understanding of their body and social acceptance from their participation within team-based sports/events. This ideal is drilled/indoctrinated into them from birth as the ideals of being a man, along with career goals, competitiveness, courage, physical strength and aggressiveness (Kearney-Cooke & Steichen-Asch, 1990). Failure to reach these goals is likely to result in isolation and potentially problematic behaviour. Connell’s (1995) theories on Hegemonic Masculinity are the most widely accepted explanations of the construction of masculinity within the western world (Jefferson, 2002). The study of masculinity in western academia has become more important since the rise of feminism in the 60s and 70s (Schrock and Schwalbe, 2009). Early studies involving masculinity were often based around gender equalities within western societies. However, Carrigan et al.’s (1985) article “Toward a New Sociology of Masculinity” initiated masculinity studies, moving away from sex-role theory, as it was not solely about power relations between men and women, but between men and men, and promoted the examining of masculinity, not as a trait but as a collection of male practices.

1.4.2.1 - Defining Masculinity

Masculinity is in some ways un-definable with theories and discussion reaching out in many different directions. Flood (2003), in a review of masculinity studies, suggested that “the best kept secret of literature on men and masculinities is that we have very little idea of what we are talking about when we use the term masculinity” (p. 203). Similar views were expressed by Connell (1995). Flood (2003) tried to categorise the differing theories and identified three clusters he believes define masculinity: (1) Beliefs, ideals, images, representations and discourses about men; (2) Traits differentiating men from women; and (3) Powerful men or strategies for maintaining men’s power.

1.4.2.1.1 - Hegemonic Masculinity

As suggested previously the most widely accepted theory of masculinity is Hegemonic Masculinity, a term refined by Connell (1995) and Connell and Messerschmidt (2005). The term Hegemony is often linked to Marxist theory and the work of Antonio Gramsci,
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relating to power and control (Chandler, 2014). Connell (1995) defined Hegemonic Masculinity as;

the configuration of gender practice which embodies the currently accepted answer to the problem of the legitimacy of patriarchy, which guarantees (or is taken to guarantee) the dominant position of men and the subordination of women (p. 77).

In layman’s terms gender is used as a tool to ensure the continued dominance of men within society. However, Connell (1995), in this early definition, neglects to acknowledge not all men will be within the hegemonic grouping and those who are not will also find themselves subordinated

Connell and Messerschmidt, (2005) redefined aspects of Hegemonic Masculinity, keeping the main tenant of the original theory; society is made up of a number of masculinities within a hierarchy that is, through time and socio-cultural factors, able to change. They rejected Connell’s (1995) original ideas of Hegemonic Masculinity being a single pattern of global dominance and put forward new ideas for studying hegemony. These new ideas were based around four concepts:

- Gender Hierarchy: In that masculinity, its construction and motivation varies from area to area, as well as how the changing role of women affects masculinity.
- Geography of Masculinities: Hegemonic Masculinity must be viewed at three levels; local, regional and global.
- Social Embodiment: examining how men’s bodies are examined and used in the creation of masculinities.
- Dynamics within Masculinity: examining the internal complexity of masculinities.

Hegemonic Masculinity is an idealised form of masculinity at a given place and time (Connell 1995); in short it is the how men are perceived within a given society/group (Connell and Messerschmidt, 2005). However, through its ideology it legitimises the subordination of non-hegemonic men and women. Ricciardelli and Clow (2010) define hegemonic masculinity as “signifying culturally normative and influential ideas of masculinity” (p. 64). Generally, the socially endorsed view of masculinity is through roles, status, perspectives, characteristics and behaviours. Although most men will never achieve
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Figure 3 - The Relationships of Connell's Masculinities Adapted from Lusher & Robins, (2009)

H represents hegemonic masculinity, C for complicit masculinity, M for marginalised masculinity and S for subordinate masculinity. A + or - shows if the relationship is one of alliance (+)-

Whilst accepting Connell’s work (1995; 2005), Schrock and Schwalbe (2009) question this approach, arguing the creation of multiple masculinities has: diverted attention to the differences of these masculinities rather than identifying the similarities; diverted attention from masculinity being a tool of domination; and detached men from responsibility for their actions.

1.4.2.1.3 - Dominant Masculinities – Striving to Be Hegemonic

Connell (1995) did not originally show clearly the conflict between different masculinities, but in refining her argument (Connell & Messerschmidt, 2005) added the geographical layers (global, regional and local) which allow for societal complexities; rather than there being one single hegemony there can be multiple ones depending upon a person’s interactions at a particular time. Within different societal groupings there are different masculinities which vie at different times to be more dominant than others. Although these masculinities may differ they will share traits or be based upon what is considered hegemonic (Ricciardelli and Clow, 2010). Within western society, three main masculinities men generally tend to aspire to, consciously or unconsciously, have been identified. These are Muscularity, Metrosexuality and Laddism, with each category having its own ideals. Laddism (New Lad) and Metrosexuality (New Man) are considered dominant masculinities within the UK (Gill, 2003).

Muscularity, is a form of masculinity whereby the man strives to achieve a muscular physique and through this he is able to demonstrate his ‘manliness’. Metrosexuality (New
Man) is a form of masculinity, developed in the 1970s and 80s, promoting the idea of having equal relationships with others. Metrosexuality is shown through self-presentation, appearance and grooming, which leads to a demonstration of power through consumerism, status symbols and employment. Laddism (New Lad), which evolved in the 90s within the UK, is characterised by youthfulness, hedonistic consumption, bachelorhood and the objectification and sexual conquest of women (Ricciardelli and Clow, 2010). Gill (2003) describes this culture more colourfully as “pleasure seeking, post-feminist if not anti-feminist, (where) his main concern is drinking, football and womanising” (p. 37).

1.4.2.2 - Dominant Masculinities and the Relationship with Body Image

In an exploration of men’s lifestyle magazines Ricciardelli and Clow (2010) demonstrated Muscularity, Metrosexuality and Laddism all promote the importance of the ideal body; in Muscularity, it is important to be muscular, in the other two there is an emphasis on weight loss to remove body fat and being toned. Metrosexuality requires men to become more confident and comfortable which in turn will lead to more sexual relationships, whereas the Laddist forgoes the confidence and goes straight to the sexual conquest, the assumption being that is how the ideal bodied male gets the girls. Ricciardelli and Clow (2010) suggest Laddist magazines tend to be derogatory about people who are overweight. All three masculinities promote the idea that masculinity, happiness and power stem from having an ideal body. This increase in pressure on men to be body conscious may offer one explanation as to the increase of male EDs, as it mirrors the inception of the disorders in women.

Traditionally, masculinity is seen through a number of traits, amongst which are strength, power, stoicism, action, control, independence, self-sufficiency and mate-ship (Barker, 2007). If serious illness impacts such traits, such as the loss of physical strength and power, or the indirect loss of power within relationships at home or work, masculinity is compromised and there is a loss of control and self-sufficiency. Due to the connotations of EDs being a ‘women’s illness’, and through this the potential loss of mate-ship, it is not surprising that men with EDs may not come forward because of the stigma of ‘not being a man’.
1.4.3 - STIGMA, MENTAL HEALTH AND EATING DISORDERS

Stigma associated with mental health is an area where a lot of work has been undertaken, with Morris (2006) suggesting that stigma further promotes feelings of low self-esteem and isolation and, as a result people are less likely to seek help. Many academics have argued a significant barrier for men with EDs accessing treatment has been stigma/ignorance from health professionals whose own views on masculinity rule men out as suffers of an ED (Duker and Slade, 2003; Treasure, 2005; Peat et al., 2008; Ousley et al., 2008). Whilst this may indicate the spread of capital and the acceptance of stereotypical masculinities within wider society, it also introduces the notion of stigma, and with regard to the evidence above, professional stigma. While stigma can be a problem in male illness per se, it is evidenced in male EDs, and affects masculinity (Charmaz, 1995; Courtney, 2000).

If stigma relating to mental illness is to be challenged, the public need to be shown that those who experience mental illness are human, and one way of achieving this is through personal stories (Morris, 2006). Ridge et al. (2010) argued that exploring personal experience relating to distress among men is an important area for critical sociological research; suggesting little is known about men’s subjectivities or the meanings they give to, and how they cope with, or seek help for, distress. As EDs are recognised as mental illnesses those who experience them often face stigma associated with mental ill-health as well as the particular stigma of being a man with an ED.

To advance the status of Male EDs, a new approach needs to be examined which will challenge the ‘Cultural Expectations’ highlighted by government in response to an on-line petition and reduce the stigma men face (Prime Minister’s Office, 2010). Over the past 30 years evidence has been available that suggests stigma caused by EDs has led researchers to believe the number of men with EDs is considerably higher than in published statistics (Andersen and Mickalide, 1983; Copperman, 2000; Duker and Slade, 2003; Soban, 2006). Likewise, it has been argued that lower numbers of men with EDs present to health services than the actual number of men who have these illnesses due to stigma and ignorance (Cooperman, 2000; Paterson, 2004; Soban, 2006).

According to Crisafulli et al. (2008) both males and females with EDs may receive little support from the wider community. Crisp (2001) found that 33% of people believed that...
people with EDs are to blame, with 35% of people questioned believing they should “pull themselves together”. Stewart et al. (2006) reported a belief whereby people with anorexia are more to blame for their condition than those with asthma or schizophrenia. Mond et al. (2006), in a sample of U.S. college-based women, found that two thirds of respondents believed that people with anorexia were to blame for their condition. Whilst admittedly an older study, Fleming and Szmukler (1992) found that 60% of medical and nursing staff in a hospital believed people with anorexia were responsible for their condition, reiterating the professional stigma evidenced in the previous section. Crisafulli et al. (2008) found that showing people the biological and genetic, rather than socio-cultural reasons for anorexia, resulted in better attitudes towards people with this illness, suggesting this was in line with how schizophrenia was de-stigmatised.

As demonstrated throughout this section, media in relation to health and stigma is extremely important. For example, headlines in mainstream newspapers such as the Sun’s “Bonkers [Frank] Bruno Locked Up” reinforced the stigmatisation of mental illness and all who are mentally ill (Morris, 2006). Morris (2006) contrasted the Sun’s headline with Now magazine’s “Frank’s Biggest Battle Yet”, a headline which had a positive construction, humanising him by using his first name and focusing on his ability to overcome his illness. The U.K. based eating disorder charity (Beat, 2011a) released media guidelines stressing the effect of negative headlines on sufferers and public perceptions, and the importance of people involved in health actually making attempts to positively “market” illness.

In health promotion, it is still unclear if it is better to promote health awareness positively, such as ‘If skin cancer is detected early it can be treated before it becomes life threatening’, or negatively as in the case of ‘If skin cancer is not detected early it cannot be treated before it becomes life threatening’ (Rothmam and Salovey, 1997). Whilst there is much work to be done, specifically to identify outside influences on decision making, the assumption that outlining positive connotations, such as early detection will save life, are more likely to be positively received, and do have weight in terms of promoting healthy behaviour (Rothmam and Salovey, 1997).

Corrigan and Penn (1999) suggest there are three basic ways in which stigma can be reduced; protest, education and contact. Protest involves negative coverage of mental
health issues which hamper efforts to achieve more positive attitudes (Priebe, 2003). Large numbers of positive examples, as well as critical feedback, are needed when portrayals are less than accurate. Education, related to stigmatising opinions, in most instances, is based upon incorrect stereotypes about mental disorders (Crisp, 2001). If this is to be addressed, more than education is needed to increase knowledge. While professional education may enable people to better understand the physiology and symptomatology of an illness, it does not address the sufferer’s emotional experiences (Morris, 2006). Finally, ‘contact’, in order to de-stigmatise mental illness, is essential (Morris, 2006). The media plays a vital role with regard to contact, as it is the easiest way to reach a large audience. Contact is provided by autobiographical and documentary accounts, focusing on lived and felt experiences of those who are stigmatised, framed in a manner which will foster empathy from the recipients. The aim of this study is to access the lived experience of men with EDs through narrative interviews, providing more ‘contact’ with men. This will hopefully lead to a better understanding of men living with an ED, whereby academic research can further investigate and, in the long term, increase knowledge and understanding, and reduce stigma for this group of people.

1.4.4 - STIGMA AND CAPABILITY AT WORK

1.4.4.1 - The Clothier Report

Capability to work based upon mental illness is a thorny, complex issue, requiring much more depth and discussion than that afforded within this thesis. The question of capability and, in some instances stigma, stems from the fallout and confusion of the Clothier Report of 1994, which examined the murders and attempted murders of thirteen children committed by a nurse, Beverley Allitt.

The report had a number of recommendations to help protect patients; which included the exclusion from training of people who had “excessive absence through sickness, excessive use of counselling or medical facilities or self-harming behaviour” (HC Deb, 1994). During the data collection phase of the investigation EDs were given as examples of self-harming behaviour (Jenkins, 1997; Launer, 1998). As well as this it became public knowledge that before Allitt’s trial, and during imprisonment, she had been diagnosed with anorexia and subsequently missed a number of days in court due to the illness. With her ...
alleged history of mental health issues, as well as being dubbed by the press the “Angel of
Death”, it is easy to imagine heightened tensions towards people with mental illness and
eating disorders who could be deemed guilty by association.

1.4.4.2 - The Consequences of Clothier, and its current relevance

The consequence of this confusion, in the wording of the law, and the reported health
problems of Allitt, was a reaction against people with mental health issues, including EDs.
Evidence of this is primarily based within the health profession, in which the Clothier
Report focused, but it must be acknowledged there are many professions whereby people
have duties of care over others. Launer (1998), wrote of his dealings with a bulimic female
who had been turned down for a nursing position, by two teaching hospitals, due to her
bulimia in the wake of Clothier. Launer (1998) argued that whilst the law did not bar
people with eating disorders, managers seemed to. He further criticised the Clothier report
stating that of the 94 witnesses called, not one had a psychology or psychiatry
qualification.

The one point of the Clothier report that seemed to bring the least dissent, was the
recommendation that people with mental health problems should not be accepted for
training without being able to prove being clear of illness for two years. The silence may
go some way to indicate that capability, or lack of it, to work can be an issue. However,
there was no mention of health professionals who also experience EDs, and how they
might function in their current role. This particular element of the Clothier Report was
abandoned by the NHS in 2002 (Wray, et al., 2005), as it had led to people being excluded
from employment through the use of inappropriate criteria and reluctance of NHS
employees to discuss their disability issues.

What was/is worrying was that in 2007, thirteen years after Clothier and five years after
Wray et al. (2005) had looked at NHS practices, the Disability Rights Commission (2007)
released a report heavily criticising the Clothier report and presenting evidence of
continued disability/mental health issues. The report found inconsistencies between
evidence, analysis and recommendations, and noted how the Clothier Report had caused
“stigmatisation of people who have, or have had, mental health problems” (Disability
Rights Commission, (2007), p. 8) and caused people to be reluctant to come forward with
their mental health issues. The DRC’s final conclusion upon Clothier is extremely pertinent and can leave the reader in no doubt as to the panel’s feelings;

The Clothier report has had a lasting effect. Despite more than a decade of legal and social progress for disabled people, the perception still remains that disability, particularly a mental health condition, automatically means the presence of risk. (Disability Rights Commission (2007), p. 20)

1.4.4.3 - EDs and their Effect on Capability and Employment

Within this section (1.5) the long-term implications of the Clothier Report for those who experience mental health problems have been outlined. It could be argued that the Clothier Report (1994) and the subsequent Bullock Report (1997), both of which contradict current disability and discrimination legislation and policy, are now obsolete. However, their legacy appears to remain evident in some areas of employment. The significance of this situation for this study lies in associations between EDs and self-harm, and how this has the potential to impact on employment for men who experience EDs.

Whilst it is unlikely that a person will be officially rejected for a position because of mental illness, the cost of mental illness to employers cannot be ignored. Estimates of the costs of all EDs to the U.K. economy are in the region of £15 billion per year, with between £6.8 to 8 billion in lost revenue (Employers Network for Equality & Inclusion, 2016). In addition, even with anti-discrimination laws, the NHS reported statistics across all fields of employment indicating that 47% of people with a mental health problem had experienced discrimination within work, whilst 37% had experienced discrimination searching for employment (NHS Employers, 2008).

The national ED charity Beat, in conjunction with the Employers Network for Equality and Inclusion, produced a guide for employers (Employers Network for Equality & Inclusion, 2016) about EDs and the ramifications for employers. Within the guidelines were sections on the impact of EDs within the workplace and effects on performance, stating the employers should be aware of signs of an ED such as fainting, excessive toilet breaks and reduced work quality. Furthermore, if the employee is giving cause for concern there should be appropriate meetings to address issues. Although not using the term ‘capability’ the message is clear; people with EDs (as with many health conditions) may experience stigmatisation on the part of employers and/or reduced work performance, and
as such, considering the amount of time adults spend at work, it is an area of lived experiences which need investigation.

1.4.5 - THE BIOLOGY OF HUMAN STARVATION

The literature review presented in Chapter 2 examines specific research published between the years 2000 and 2016, on male anorexia. In many of the papers reviewed an assumption is made regarding the biological and physiological effects of EDs, and the reader automatically understanding there is a relationship between weight reduction due to starvation and physical and mental distress. Based on my personal experiences and the primary research reviewed in this thesis, these clinical descriptions (if A happens then B will follow) can at times be taken for granted without fully understanding the human aspects of the story and how such things are known.

Professor Janet Treasure’s (2005) book ‘Anorexia Nervosa, A Survival Guide for Families, Friends and Sufferers’ was, in my own struggle with EDs, a valuable tool in helping to understand why some of the things which I had experienced happened. Treasure, a Professor at King’s College London, wrote chapters detailing the effects to the body and the mind when a person with anorexia is in a process of starvation and semi starvation. Treasure recommended for further reading Keys et al. (1950) ‘The Biology of Human Starvation’, and although in academic terms old, it is still a seminal piece of research, with Chin (2015) suggesting there are no other studies like it. Much of our knowledge about the effects of starvation stem from Keys et al.’s (1950) research and the men who volunteered for the study. Keys et al. (1950) presented data on anorexia and noted that the experiment duplicated anorexia more than it did the famine conditions it was trying to replicate, due to normality and medical care available to men that would not be available in a famine region (Tucker, 2006).

1.4.5.1 - The Minnesota Starvation Experiment

Conducted within the latter years of the Second World War the Minnesota Starvation Experiment, published in 1950 as the Biology of Human Starvation, was a concerted effort to understand the effects of human famine, which had been seen a number of times in recent memory. With the war drawing to a close and knowledge of the
POW/work/concentration/extermination camps and millions of people becoming refugees, the study was aimed at trying to understand starvation and effective re-feeding in rebuilding the war-torn populations. Keys et al.’s (1950) work was divided into two distinct parts: an experiment took place where, over a period of a year, the participants were semi starved and then re-fed; a second part of the study was a literature review of the published work which examined previous famines and states of starvation.

The literature review showed how sexual interest was lost or limited, even thoughts or sexual joking/flirting stopped. Keys et al. (1950) presented evidence from Germany of testicular atrophy in men, and from the Dutch famine they noted menstrual disturbances and amenorrhoea being widespread. The review noted how semi starvation resulted in the impairment of coherent and creative thinking, confusion and loss of concentration, the lowering of emotional responses, depression, fatigue, apathy, irritability and finally a preoccupation with food to suppression of other activities. The main focus of the study was a year-long experiment using 36 volunteers from the ranks of conscientious objectors. The study was split into four sections with the men living on the University of Minnesota’s campus. They were able to take classes and live normally, although they had to walk 22 miles per week and were only able to eat the meals given by staff. An outline of the research protocol was as follows:

- A Control Period of 12 weeks enabled base line data to be collected.
- A Semi-Starvation Period lasting 24 weeks, the aim of which was for each man to lose 25% of their body weight, with the food they were given being what would be available in a European famine situation.
- The Restricted Rehabilitation Period lasted 12 weeks with the volunteers being split into groups and given different diets to establish strategies to use in real situations.
- The final period was entitled the ‘Unrestricted Rehabilitation Period’ and in this period of 8 weeks the men were able to eat as they wished, whilst still being monitored.

Keys et al. (1950) reported 97% of the men became less sociable, 93% lost sexual drive, 93% became apathetic and depressed, with 85% encountering periods of indecisiveness. The men experienced lower strength and energy levels, tiredness, their hearts shrunk, the
heart beat slowed and blood volume reduced by 10%, along with other metabolic changes thought to conserve energy. There were reports of increased dizziness, muscle soreness, reduced coordination, skin problems, hair loss, ringing in their ears and constant coldness. A further and quite striking finding was how little weight (7%) had to be lost in some of the men to produce emotional deterioration which interfered with the volunteer’s day to day functioning. This was found in 20% of the men. This is quite startling given the 15% weight loss figure before consideration of anorexia in the DSM-4 (2000). Keys et al. (1950) reported that a number of the men who had taken up college classes whilst taking part in the study had to drop-out as they did not have the energy to concentrate or the motivation to go to class. A final twist was that a number of the men began to suffer from distorted body image; rather than seeing themselves as being very thin, as images showed, they saw others as being fat.

1.4.5.2 - The relevancy of Keys et al.’s (1950) study today

The Minnesota Starvation Experiment has enhanced our understanding of the way in which starvation affects personality, the mind and body (Kalm and Semba, 2005). It helped to change the scientific field’s attitudes to how the body is able to adapt and mutate to cope with different events/extremes. Even though the study was published nearly 70 years ago it is still as relevant today as it was in 1950. Keys et al.’s work provided a rationale for clinicians trying to restore weight before attempting to make meaningful psychological changes (Tucker, 2006). Whilst writing the study up, Keys et al. also noted a link between lowered heart attacks and food deprivation, linking fatty foods to heart disease, which became the focus of his research up to his retirement (Tucker 2006).

1.5 – CHAPTER SUMMARY

The intention of this chapter was to provide context and theoretical background to the ideas, methods and questions which follow. The evidence presented in this chapter indicates there is a larger percentage of men affected by EDs than previously thought (Braun et al., 1999; Hudson et al., 2007; Skolnick, 2014). However, if this is because more men are experiencing EDs or that men are more aware of them and therefore engaging with health services is not, nor never, will be known.
Bourdieu’s (1986) notion of “capital”, the day to day learning and experiences people encounter, influences thinking and reactions to such thoughts. The media is one of the main ways in which capital is spread and as such harnessing this to reduce stigma is one of the ways in which negative attitudes towards mental illness can be reduced (Morris 2006). However, in terms of men in society, masculinity continues to impact the belief system of men, who they feel they are, and how they believe they should act. At the top of the hierarchy is the Hegemonic male (Connell, 1995; Connell and Messerschmidt, 2005), with men striving to fit into this classification as it is considered the key to success, financially and sexually. However, whilst most men will never be in this group, some men in lower classifications ape hegemonic behaviour as much as they can; others reject it, and for others the emasculation causes problems. For men with EDs, masculinity appears to be compromised by having what is stereotypically viewed as a female illness, a mental illness, and also by having little or no interest in sex or relationships or confidence to engage in them. In combining theories of capital and masculinities it can be argued that our personal capital is influenced by the messages we receive through our interactions with others and through this our ideas of masculinity are formed. However, it must also be acknowledged, just like hegemonic masculinity, the dominant organisations within society influence capital. By understanding these theories there may be an increased awareness of male EDs and a reduction in related stigma.

The next chapter presents a review of the current academic literature in the field of male EDs, specifically relating to anorexia and non-specified form of anorexia. The review demonstrates current thinking from studies focusing on men, as well as illustrating the justification of this research project and how it will add a unique perspective to the limited body of knowledge.
CHAPTER 2 - LITERATURE REVIEW

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons
2.1 – INTRODUCTION

A literature review is one of the cornerstones of undertaking research, whether it is a PhD study such as this or a large funded project in a particular field. A literature review seeks to establish the current research that is relevant to the topic area, as it allows the researcher to refine or create research questions and focus arguments. For the reader, it allows a synopsis of the relevant academic work to be collated within one document. This is increasingly important in an age where even the most conscious person will be unaware of all the research studies within a particular subject (Aveyard, 2007).

This literature review had the following objectives:

- To examine the current academic literature, described by Griffiths et al. (2013) as “sparse”, around the subject of men (over 18) who have an eating disorder, specifically anorexia or a non-specified form of anorexia, with a particular interest in the lived experiences of these men.
- To identify the themes which emanate from these studies.
- To identify any ‘gaps’ in the current research.
- To provide evidence as to where this research fits with current research, thus adding to the small, but growing body of knowledge.

To meet these objectives in a reliable way the information used must be collected in such a way so that researchers in the future can replicate results (Krefting, 1991). This required a rigorous approach, and when undertaking the following review, a systematic approach was used.

Aveyard (2007) suggested that within Health and Social Care the best way to conduct a literature review is to follow the principals of the Cochrane Collaboration, an independent non-profit organisation, consisting of health practitioners, researchers and patient advocates, whose aim is to assist in the decision-making process by providing research evidence, predominantly through systematic reviews. The Cochrane philosophy is that a review should be:

a high-level overview of primary research on a particular research question that tries to identify, select, synthesize and appraise all high ‘quality’ research evidence relevant to that question in order to answer it. (Cochrane, 1999).
Data for this review has been collected in a number of academically recognised ways. Firstly, via systematic searches of academic databases, secondly a hand search of eating disorder specific journals was undertaken; and thirdly other resources, such as the media and the reference lists of identified journal articles were explored. To keep the literature review ‘relevant’ it was agreed with the supervisory team to focus on literature published this century. At the cut-off date (December 2016) 61 published papers were identified as appropriate, as they specifically relate to Male ED. Of these, ten were single patient case studies, a further three case studies were found reporting on two, four and five men respectively.

2.2.1 - ACADEMIC DATABASE SEARCHES

Initially, published literature was identified via academic databases (Ovid Medline, EBSCO Medline). To undertake this, a number of key word searches were instigated using all academic databases including PsycARTICLES, PsycEXTRA and PsycINFO via the Medline platform. The same searches were run using both the Ovid and EBSCO search functions and the criteria below.

- Keyword searches were undertaken looking for anorexia and men, and anorexia and male within the titles.
- Searches were restricted to articles published in English between January 2000 and December 2016.
- Articles which did not feature adult males (>18) were excluded.
- Duplicated articles were excluded.

2.2.2 - HAND SEARCH

The Medline keyword search allowed a number of ED specific academic journals to be identified. A “systematic hand search” of specific ED journals was undertaken to locate studies that could be useful within this literature review. The hand search looked at every journal article between 2000 and 2016 and it allowed a wider range of articles to be selected. Abstracts were read enabling articles with eating disorders in the title to be selected.
considered for their relevance. The journals examined were; The International Journal of Eating Disorders; The European Eating Disorders Review; Journal of Eating Disorders (On-line, created 2013); Eating Disorders The Journal of Treatment and Prevention; and Advances in Eating Disorders Theory, Research and Practice (Created 2013).

2.2.3 - OTHER RESOURCES

The final method used to gather data for this literature review was to make use of the media and the references cited in the previously identified published work. For example, an article on the BBC website, “Eating disorders in young men are being overlooked” in April 2014, allowed the following of links to find the research article by Räisänen and Hunt (2014) in the British Medical Journal (Open Access) which had been used as evidence for the journalist’s article.

2.3 – STUDIES SELECTED FOR REVIEW

2.3.1 - BREAKDOWN OF STUDIES

In total 60 studies were identified, with an additional four literature reviews which were not used within this chapter. Of the studies identified, 39 were quantitative, three studies were described as mixed method studies and 17 were qualitative. However, of 17 qualitative studies, 13 were case studies (10 involving only one man). For a full breakdown of the academic studies selected for this review please see appendix 1.
2.3.1.1 - Studies Published by Year

The following graph shows the breakdown of studies used in this review by the year they were published. With the exception of 2012 and 2014, when fifteen and eight studies respectively were published, academic output has been stagnant, averaging 3.5 studies per year. Removing 2012 and 2014’s studies sees the average drop to 2.6 studies per year. This indicates that despite a number of studies in the review (Cooperman, 2000; Mitchison et al., 2013; Räisänen and Hunt, 2014) calling for more research in male EDs, these hopes have not seen fruition.

Figure 4 - Academic Studies Used Published by Year (post 2000)
2.3.1.2 - Studies Published by Academic Source

Table 1 (following page) shows where the studies used in this review were sourced. Unsurprisingly 41 of the 61 (67%) articles in this literature review came from four of the five ED journals identified in this review’s methodology. However, no studies were used from the Journal of Eating Disorders.

**Table 1 - Studies Used by Publication**

<table>
<thead>
<tr>
<th>Academic Source</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>International Journal of Eating Disorders</td>
<td>27</td>
</tr>
<tr>
<td>European Eating Disorders Review</td>
<td>7</td>
</tr>
<tr>
<td>Eating Disorders</td>
<td>5</td>
</tr>
<tr>
<td>Advances in Eating Disorders: Theory, Research and Practice</td>
<td>2</td>
</tr>
<tr>
<td>Acta Derm Venereol</td>
<td>1</td>
</tr>
<tr>
<td>Acta Orthopaedica Belgica</td>
<td>1</td>
</tr>
<tr>
<td>American Journal of Medicine</td>
<td>1</td>
</tr>
<tr>
<td>Appetite</td>
<td>1</td>
</tr>
<tr>
<td>Australian Psychiatry</td>
<td>1</td>
</tr>
<tr>
<td>BMJ Open</td>
<td>1</td>
</tr>
<tr>
<td>Body Image</td>
<td>1</td>
</tr>
<tr>
<td>Child and Adolescent Psychiatry and Mental Health</td>
<td>1</td>
</tr>
<tr>
<td>Current Sports Medicine Reports</td>
<td>1</td>
</tr>
<tr>
<td>Danish Medical Bulletin</td>
<td>1</td>
</tr>
<tr>
<td>Eating Disorders Association (now Beat) Report</td>
<td>1</td>
</tr>
<tr>
<td>International Journal of Psychiatry in Medicine</td>
<td>1</td>
</tr>
<tr>
<td>Journal of Health Psychology</td>
<td>1</td>
</tr>
<tr>
<td>Journal of the Royal Society of Medicine Short Reports</td>
<td>1</td>
</tr>
<tr>
<td>PLoS ONE</td>
<td>1</td>
</tr>
<tr>
<td>Psychology of Men and Masculinity</td>
<td>1</td>
</tr>
<tr>
<td>Sex Roles</td>
<td>1</td>
</tr>
<tr>
<td>Smith College Studies in Social Work</td>
<td>1</td>
</tr>
<tr>
<td>The Journal of Nervous and Mental Disease</td>
<td>1</td>
</tr>
<tr>
<td>The Journal of Sexual Medicine</td>
<td>1</td>
</tr>
</tbody>
</table>
2.3.1.3 - Location of Studies Used

It is not surprising that with one of the search criteria being that the study must be written in English or translated into it, over half of the studies used come from English speaking countries such as U.S.A, U.K and Australia. However, studies come from all continents excluding Antarctica and Africa, indicating male EDs are a global phenomenon.

**Table 2 - Breakdown of Studies Used by Country**

<table>
<thead>
<tr>
<th>Country</th>
<th>Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>U.S.A.</td>
<td>22</td>
</tr>
<tr>
<td>U.K.</td>
<td>10</td>
</tr>
<tr>
<td>Spain</td>
<td>4</td>
</tr>
<tr>
<td>Italy</td>
<td>4</td>
</tr>
<tr>
<td>Australia</td>
<td>3</td>
</tr>
<tr>
<td>Austria</td>
<td>2</td>
</tr>
<tr>
<td>Finland</td>
<td>2</td>
</tr>
<tr>
<td>France</td>
<td>2</td>
</tr>
<tr>
<td>Argentina</td>
<td>1</td>
</tr>
<tr>
<td>Brazil</td>
<td>1</td>
</tr>
<tr>
<td>China</td>
<td>1</td>
</tr>
<tr>
<td>Denmark</td>
<td>1</td>
</tr>
<tr>
<td>Germany</td>
<td>1</td>
</tr>
<tr>
<td>Iraq</td>
<td>1</td>
</tr>
<tr>
<td>Japan</td>
<td>1</td>
</tr>
<tr>
<td>Mixed - Australia, U.K., USA, Singapore</td>
<td>1</td>
</tr>
<tr>
<td>Mixed - U.K. and Spain</td>
<td>1</td>
</tr>
<tr>
<td>Mixed - Worldwide Mainly Australia, USA and UK</td>
<td>1</td>
</tr>
<tr>
<td>Sweden</td>
<td>1</td>
</tr>
<tr>
<td>U.A.E.</td>
<td>1</td>
</tr>
</tbody>
</table>
2.4 - STUDY FINDINGS

2.4.1 - INTRODUCTION

In reviewing the literature regarding male EDs, one of the most popular themes within academic research appears to be that of examining the similarities and difference between eating disorders in males and females. This is not surprising as many of the earlier studies, even those that have a focus on male EDs, seem to use a female sample for comparison. The general consensus is, in terms of the effects and contributing factors, eating disorders are not gender specific and many of the studies have, within their findings/conclusions, highlighted this (Cooperman 2000; Striegel-Moore et al. 2009; Núñez-Navarro et al., 2012; Mitchison et al., 2013). Whilst Cooperman (2000) found considerable overlap between risk factors and onset, Striegel-Moore et al. (2009) concluded that "the gender differences in disordered eating are less pronounced than what previous studies had assumed" (p. 474). More recently, Mitchison et al., (2013) suggested that “there were no significant sex interactions for the ED features measured, implying that in general ED features are as debilitating for men as they are for women” (p. 378). Mitchison et al. (2013) believe both males and females who have an eating disorder have a reduced quality of life. Weltzin et al. (2012) suggest evidence shows similar recovery rates between males and females.

Other studies reporting on the similarities between men and women with EDs include; Strober et al. (2001), Fassino et al. (2001), Fernández-Aranda et al. (2004) and Smith et al. (2010). Strober et al. (2001) examined the occurrence rate of anorexia in relatives of men with EDs; they found the incidence of this was 20 times higher than in the control group and only female relatives had suffered. These findings were similar to studies of this nature relating to females with EDs and their relatives. Fassino et al. (2001) found men diagnosed with anorexia shared more traits with their female counterparts than they did with healthy men. This recurring theme was further evidenced by Fernández-Aranda et al. (2004) who found no significant differences between the genders, with the exception that males tended to have been overweight before their illness, and that they are shyer around strangers. MacCaughelty et al. (2016) found being overweight was likely to result in a non-referral to a consultant, as symptoms may be missed/or not deemed severe enough. Weltzin et al.
An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

(2012), that found on admission to ED residential inpatient units men tended to have higher levels of co-morbidity than women. They also noted that, upon admission, 30% of their sample were not taking psychotropic medication, stating the reasons for this were open to interpretation.

Strumia et al. (2003) indicated that men do not seem to share, or it is difficult to distinguish, the coetaneous issues associated with women, such as the growth of downy hair, hair and nail fragility, and/or lesions on the hands caused by induced vomiting. A study undertaken by Smith et al. (2010) found that men with low pre-natal testosterone were more likely to have an eating disorder. Interestingly, part of this information was gathered by examining the ratio between subjects’ 2nd (index) and 4th (ring) fingers, a strategy which has been used by academics to examine many things including mental, and specifically eating, disorders (Smith et al. 2010). It is suggested that growth of the ring finger is governed by testosterone while growth of the index finger is governed by oestrogen, with each of these hormones having an impact upon sexual development.

However, Smith et al. (2010) suggest that these findings are in line with similar work undertaken by Klump et al. (2005) on females. Mitchell et al. (2014) acknowledged that important differences between genders have emerged, including differing body ideals and presenting symptoms, but such differences are not shared.

One problem with gender comparisons is that the (quantitative) statistics used to show severity in male eating disorders are skewed, as the instruments used to take such measures are often developed from a female perspective. Stanford and Lemberg (2012) found that males scored much lower on such tests because EDs manifest themselves differently in men, and clinicians are looking for the wrong criteria. For example, Stanford and Lemberg (2012), used the Eating Disorder Risk Composite questionnaire to test drive for thinness, with men producing a low score as their drive is towards muscularity. In the same questionnaire, men diagnosed with bulimia scored low, because in men purging is much more likely to be from exercise rather than from vomiting or laxatives as women do. In Kiraly and Joy’s (2003) case study of a male tri-athlete, they questioned the validity of female specific tests (Eating Disorder Inventory and Eating Attitudes Test) on male subjects.

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An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons
In reviewing the available literature, a number of male specific sub themes emerged from the findings and these are presented in the following sections of this literature review. The themes have been grouped together to increase understanding. The first section examines demographic information from the studies, namely age and weight at onset of the ED. The second section focuses on the rationales as to why men engage in EDs and the main methods they use to control their weight. Socio-cultural factors appear to play a role in all eating disorders and the third section examines those which are common themes across the studies identified. These socio-cultural factors range from mental illness and obesity within the family to concerns relating to masculinity. The fourth section examines some of the psychological issues that have arisen within the studies, ranging from self-harm to the behavioural characteristics which are present in people with EDs or which come to the fore during the duration of the illness. Throughout the period of EDs being examined through the auspices of research, there has been an interest in the psychological and biological effects of the illness on libido/sex/relationships. The studies in this review are no exception, and they show that men with eating disorders are generally single and the prognosis for recovery is better if, before the eating disorder occurs, they were sexually active. The penultimate section of the review highlights research studies similar to the research undertaken in this study, namely using qualitative research methods to investigate the lived experiences of people who have an ED. They differ from this study in terms of the demographics of the participants and, they also focus on and around experiences of treatment. The final section of this literature review examines the limitations of the studies used, as identified by their authors.

2.4.2 - DEMOGRAPHICS

2.4.2.1 - The Occurrence of EDs in Men

Getting an accurate figure as to the numbers of men who have an ED is extremely problematic and, in general, the studies within this review have not attempted to answer this question. Button et al. (2008) suggested the prevalence of eating disorders in males between 1987 and 2007 did not increase dramatically, remaining under 10% of total reported cases, with it being 5% in 2007. Whilst Button et al. (2008) suggested these figures were in keeping with similar studies, they did add the caveat that their results did
not in any way (nor could they) show the number of men (or women) with EDs, who did not choose to come forward. Their findings are in contrast with the introductory chapter of this document, where it was suggested that EDs in men are more prevalent, 25% of presenting cases, and that social and cultural stigma are barriers to treatment (Hudson et al., 2007; Skolnick, 2014). Interestingly, many of the newer studies in this literature review quote Hudson et al.’s (2007) findings, demonstrating how opinions have changed in the time this thesis has taken to develop. MacCaughelty et al., (2016) suggested health professionals’ ignorance to be a potential barrier to treatment. This is reiterated by Cazzuffi et al. (2010) whose subject was initially treated in a gastroenterology department for his weight loss and liver problems with little success before being discharged, and then diagnosed and treated by specialist ED professionals. Raevuori et al. (2009) also concluded that anorexia in men was more common than suggested by previous reports, reiterating how difficult it is to quantify the number of men with EDs for a myriad of different reasons.

2.4.2.2 - Age at Onset

The age of onset of anorexia for men is generally slightly older than that of women. Crisp et al. (2006) found for men this was just above 20 (20.1) years of age, and for women it was 18.5 years of age. They speculated this was perhaps because males and female grow at different rates during and through puberty. These findings were replicated by Gueguen et al. (2012) who found that males were older than females by an average of 2.7 years, with the onset of EDs in males being 20.8 years and for females 18.1 years. Gueguen et al., (2012) agreed with Crisp et al. (2006) that later onset of puberty in males could be a factor in accounting for the difference between age of onset of anorexia in males and females. However, Lindblad et al. (2006), in contrast to Crisp et al. (2006) and Gueguen et al. (2012), found the age of onset of EDs to be around five years earlier for men. The reasons for this disparity are unclear. Lindblad et al.’s (2006) study was only based on inpatients (a self-identified limitation by the author) which could be suggestive of those participating having a more serious ED that was identified earlier as it warranted hospitalisation. However, this hypothesis must be treated with caution, as both Crisp et al. (2006) and Guegen et al. (2012) used clinical samples, albeit a mix of in and out-patients. Likewise, detecting EDs at a younger age might be a cultural issue, as Lindblad et al.’s (2006)
research was carried out in Scandinavia (Sweden), whilst those of Crisp et al. (2006) and Gueguen et al. (2012) were undertaken in Western Europe (Britain and France respectively). Further, an Italian study (Fassino et al., 2001) also found males having an earlier age of onset of anorexia. Fassino et al., (2001) identified males to be 16.5 years as opposed to women’s age of 18.7 years. Malik et al. (2014) suggest when anorexia manifests after the age of 25, it is called tardive anorexia (TA) and is differentiated from anorexia by the evident precipitating factors, as well as it having a depressive component. It must also be noted that literature such as Manejias Parke et al. (2008), Weltzin et al. (2012) Malik et al., (2014), Mangweth-Matzek et al. (2016) and Ochi et al. (2016) all show EDs existing in men over the age of 40 and well beyond, indicating that men of any age can be affected.

2.4.2.3 - Overweight at onset or Pre-Anorexia

One of the more distinct “differences” between the genders is that of males and females coming from markedly different backgrounds in terms of their pre-eating disorder weight. Many research studies (Cooperman, 2000; Strober et al., 2001; Fernández-Aranda et al., 2004; Raevuori et al., 2008; Raevuori et al., 2009; Gueguen et al., 2012), have demonstrated that men, unlike women, tend to have, at some point, been overweight before their illness began. Studies report this in a variety of ways. Fernández-Aranda et al. (2004), Raevuori et al. (2009) and Strober et al. (2001) used the term ‘overweight’; Gueguen et al. (2012) described their male subjects as being ‘pre-morbidly overweight’; and Raevuori et al. (2008) described their male participants as being ‘unhealthily overweight’ before onset of the ED. Cooperman (2000) was more specific, reporting men with anorexia to be 15% overweight, as opposed to women with anorexia who tend to be 10% below their ideal body weight, before becoming ill. This is something that needs further examination by researchers, as a myriad of questions spring to mind. Such questions include differences in the scales researchers use to classify obesity. For example, if the focus is BMI this does not take into account muscle mass. However, a study by Bramon-Bosch et al. (2000), directly comparing males and females with eating disorders, suggested “No gender differences were found in the current BMI or in the lowest or highest BMI ever achieved” (p. 323). This is an interesting conclusion as the studies of Fernández-Aranda et al. (2004)
and Gueguen et al. (2012) were both similar to that of Bramon-Bosch et al.’s (2000) study in terms of being clinically based and with gender mixed samples.

2.4.2.4 - The Goal of an Eating Disorder

Both Cooperman (2000) and Núñez-Navarro et al. (2012) identified one significant difference between males and females as being the “goal” of the ED. The aim of men losing weight is to become more muscular, whereas with women weight loss was correlated with the purpose of achieving thinness. In a study carried out by Dissing et al. (2011) of body image attitudes within a non-ED population, it found females have a desire for thinness whilst adopting dieting behaviour, whereas males wanted to be slim and muscular. Regardless of the different population, these findings support those of Cooperman (2000) and Núñez-Navarro et al. (2012), indicating that goals differ for men and women, and this is consistent amongst those with and without EDs alike.

Continuing on the theme of the goal of EDs, Grossbard et al. (2012) supports the previous studies, but also suggested that depressed mood is likely to play a more prominent role in men with ED symptoms than women. Grossbard et al. (2012) further explained that men focus on body and size with a drive for muscularity, linking it to masculine gender norms, and that the psychological and social benefits of this will protect from symptoms of depression. This could perhaps be a reason for muscle dysmorphia or bigorexia.

2.4.2.5 - “Magic Mirrors” – Distorted Body Image

Anorexia is associated with poor body image, and although it is not the cause of the disorder the person with the ED seems to channel their trauma into this. Mangweth et al. (2003) shows how utterly bemusing eating disorders can be. They found that men with anorexia and bulimia, when asked to choose their “ideal body” and a woman’s “ideal male body” from a computer-generated graphic, fell into a range comparable with non-eating disordered men. However, when asked to choose their own perceived body type, they chose sizes which were on average twice as large as they actually were, whereas the control group showed almost no such distortion; demonstrating the men with EDs only viewed their own size with distortion. Dakanalis et al. (2014), in a non-ED specific sample, found that men who were dissatisfied with their bodies engaged in body
monitoring. Those who, in laymen’s terms, were not as confident in themselves and who sought approval, had greater disordered eating behaviours.

2.4.3 - HOW MEN LOSE WEIGHT ASIDE FROM STARVATION

2.4.3.1 - Exercise

Excessive exercise is one of the main methods in losing weight for both genders. Dalle Gravea et al. (2008) reported this occurred in 80% of cases of acute anorexia and as such has an influence on treatment outcomes. A number of studies reiterate the use of excessive exercise as being a favoured method of men in weight control (Bramon-Bosch et al., 2000; Mangweth et al., 2003; Raevuori et al., 2008; Dissing et al., 2011; Murray et al., 2012; Younis and Ali, 2012). However, opposed to this, and in an earlier study, Crisp et al. (2006) found “there were no differences [between men and women] in respect of frequency of usual/severe diet related rituals or of excessive commitment to exercise” (pp. 164-65). Button et al., (2008) demonstrated similar findings to Crisp et al. (2006). More recently Murray et al. (2014) suggested there is no difference between men and women in terms of why they exercise, which is to control weight, but males scored much higher on mood improvement scales. Whilst biologically endorphins released during exercise improves mood. The authors warned that the use of exercise for affect regulation and mood benefits in men leads to more rule rigidity, and thus greater difficulty for clinicians in reducing harmful excessive exercising habits.

I emailed Dr. Murray, who has two studies based around exercise cited within this review (Murray et al., 2012; 2014), as I thought it may give a more definitive answer as to the differences noted by Crisp et al. (2006). I asked if the authors had noticed any difference in the rates of excessive exercise in males and females with anorexia, as they did not include or address this in the write up of their 2014 study. Dr Murray kindly replied within a few hours and wrote “I can also add anecdotally, that in my clinical experience that guys do tend to exercise more than women in the context of AN [anorexia]” (Murray, 2014, personal communication 13/07/14). Dr Murray also added a caveat, that I should try and include this area within my research as “many men with disordered eating will exercise compulsively with a view to enhancing muscle size or definition” (Murray, 2014, personal communication 13/07/14)
2.4.3.2 - Vomiting/Laxatives

Núñez-Navarro et al. (2012) found that males were more likely than women to vomit rather than take laxatives to control their weight. They found that the males diagnosed with anorexia reported more weekly vomiting than women, but less laxative abuse. However, Núñez-Navarro et al. (2012) acknowledged that there is a debate in relation to this finding within the literature. Buchanan et al. (2013) found the exact opposite to Núñez-Navarro et al. (2012). However, the former’s sample was based on people who had been sexually harassed.

Núñez-Navarro et al. (2012) argued that Hispanic males have been shown to use weight loss strategies such as vomiting more than non-Hispanic males. Button et al. (2008) also found, in their U.K. based study, that men tended to vomit more than women, although these results were across the whole pantheon of anorexia, bulimia and EDNOS. Ochi et al.’s (2016) case study subject engaged in vomiting as a form of purging.

2.4.4 - SOCIO CULTURAL FINDINGS.

2.4.4.1 - Background

The family background of a male with an ED is an area which has been investigated by a number of researchers. Crisp et al. (2006) found males diagnosed with anorexia appeared to come from a background where one or both parents had mental health problems and where there was a history of parental obesity. Interestingly, the social background of females with eating disorders has historically been seen as being white and upper/middle class (McVittie et al., 2005; Räisänen and Hunt, 2014). Tong et al. (2005) noted that anorexia and bulimia have become common in the more westernised high-income Asian countries. Lindblad et al. (2006) found the exact opposite in their inpatient based study, with men coming from lower social strata. However, Lindblad et al. (2006) qualified this by saying that it may reflect a social bias in those who receive hospital care. Crisp et al. (2006) found that a greater percentage of males in their study came from lower social backgrounds than females. Perhaps the difference in results could be due to different socio-cultural environments of the studies in question, but what the inconsistencies do highlight is a lack of knowledge regarding socio-cultural influences within male EDs.
2.4.4.2 - Geography

The effects of cultural environments on various aspects of health are legitimate. Becker et al.’s (2002) female based (discussed in chapter one) study showed how “imported” culture can influence society. Lee and Lee (2000) established female concerns over fat had become more pronounced in the more westernised Chinese cities. Likewise, Tong et al. (2005) explored the socio-cultural context of living in China, with five males aged between 15 and 23, who presented with an ED. All the participants stated that being fat was socially and psychologically unacceptable. The authors concluded that socio-cultural changes and westernization most likely account for the increased incidence of eating disorders among young males and females in China today.

A case study situated in Iraq, where Arabic tradition still dictates a sign of health and prosperity is to be overweight, again demonstrates how the adopting of a different culture can impact upon tradition. Younis and Ali (2012), who, after treating a middle class fourteen-year-old male diagnosed with anorexia, suggested that the western culture the subject and his peers (who bullied him about his weight and greed), were exposed to was a factor in the case. Likewise, Musaiger et al. (2014) cited the westernisation of the U.A.E as a reason for the growth in disordered eating attitudes and consequently EDs in both male and females in this region.

2.4.4.3 - Masculinity

Masculinity has been identified as a barrier to medical treatment per se for men, with researchers directly and indirectly examining the constructions of masculinity in relation to EDs (Courtenay, 2000). One area in particular is that of anorexia being perceived as a female illness (McVittie et al. 2005; Raevuori et al.,2008), perhaps compromising the ability of men to identify, seek help and come to terms with their ED.

McVittie et al. (2005) canvassed the opinions of 12 male students without eating disorders. All 12 students believed anorexia to be a female specific condition, and distanced men with anorexia from hegemonic men in general. This was evidenced in their explicit references to femininity and mental weakness. McVittie et al. (2005) suggested “it should come as no surprise that men construct anorexia in men as a disorder not of physiology, but rather of masculine identity itself” (p. 417). These findings parallel with Courtenay’s
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(2000) study on general health care and attitudes towards masculinity; in that succumbing to, or seeking help for illness, are signs of femininity. In a study examining male body dissatisfaction, Lavender and Anderson (2010) reiterate this view, suggesting that a breakdown in male health is an attack on masculinity itself; concluding that the traditional masculine gender role in western society causes men, who have experiences outside of this role, to suffer from emotions such as shame, guilt and anger. Such negative emotions cause some men to engage in maladaptive behaviours.

Raevuori et al. (2008) also identified anorexia as being perceived as a female illness. Three out of the five men they interviewed had not disclosed their anorexia due to feelings of shame, isolation and the double stigma of being mentally ill and being ill with a ‘women’s illness’. The perception of eating disorders being a feminine illness is a recurrent theme in the literature (McVittie et al., 2005; Raevuori et al., 2008; Räisänen and Hunt, 2014). In light of the shame attached to this type of illness, male eating disorders are under-diagnosed, untreated and under-researched (Räisänen and Hunt, 2014), hence the problems of establishing prevalence identified earlier.

**2.4.4.4 - Accessing Treatment**

The question of accessing treatment and the time lapse from onset of illness to presenting to the health services is one which, from the studies found in this review, is unclear. Cooperman (2000) reported that the mean time for a man to get help was six years; recognising that it was difficult for men to access services due to cultural expectations and professional ignorance. Räisänen and Hunt’s (2014) qualitative study does not of course provide statistical evidence, but they concluded that there is a lack of knowledge about EDs in men throughout society and there is a reticence in men to come forward due to cultural assumptions. This finding was echoed by Griffiths et al. (2015), who in a quantitative study concluded that stigma for men, (based around EDs being female illnesses, mental illness in general and masculinity of ‘getting on with things’) was a major factor in undiagnosed EDs in men. These findings appear contradictory to the findings of others, whereby men access treatment earlier than women. Gueguen et al. (2012) found that the time between the onset of anorexia and admission to hospital was just under six years for men and a little over eight years for women. However, in contrast the much earlier work of Carlat et al. (1997) found that men with anorexia only had a 2.1-year
average between onset and presentation to health providers, although for men with bulimia and EDNOS, they found an average of 8.4 years and 7.6 years respectively. This, they concluded, was because the physical changes in men with anorexia were more likely to be noticed by health professionals and family, as opposed to women with anorexia and men with bulimia and EDNOS. What is worrying from this point of view is that the reported time difference in being able to access treatment has increased between 1997 and 2012. Although a single patient case study, Kazafi et al. (2010) reported a three-year gap between onset of illness and treatment, which is broadly in keeping with Carlat et al.’s (1997) findings.

2.4.4.5 - Other Cultural Risk Factors

Cooperman (2000) reported that childhood bullying for being overweight is a risk factor, as well as body building, exercise and sports-based pressures. In the U.K. the latter is commonly associated with male dancers, long distance running and jockeys. Likewise, ski jumping is also problematic with regard to eating disorders, as the lower the ski jumpers weight the further they are able to jump. In 2004 the governing body brought in rules which linked ski length jump to body mass to reduce the benefits of low weight. However, anorexia athletica, as it has become known, is a difficult area to examine as it is difficult to distinguish between a person who is controlling their energy intake for sport and those who are doing so for other reasons. This is exemplified by Chatterton and Petrie (2013) who examined disordered eating and weight control amongst US college athletes. They found that whilst many of the students engaged in disordered eating and weight control, only 1.1% of the sample actually had an ED. Kiraly and Joy (2003) used a case study to examine anorexia within athletes. In their case study, they encountered a man with anorexia who engaged in triathlons, reporting anhedonia (reduced enjoyment), decreased libido, and decreased sexual arousal as well as cognitive disturbance stemming from disorganized thinking, whilst warning of the increased risk of EDs in men who needed to control weight or in order to perform physically.

Sexual abuse has also been identified as risk factor of EDs. Buchanan et al. (2013), highlighted the relationship between men and women who suffer sexual harassment and eating disorders, with men being more likely to use compensatory behaviours such as vomiting and laxatives to control weight, than women. Mehler et al. (2008) found 25% of
their sample who were diagnosed as being anorexic with binging and purging (ANB) reported being sexually abused, whereas none of the men diagnosed as being restrictive anorexics (ANR) did. Although this sample was small (70 men) to make generalisations, what was consistent is that both sub groups reported similar levels of excessive exercising 50% (ANB), 56% (ANR) and childhood obesity (33% both ANB and ANR).

2.4.5 - PHYSICAL FACTORS

The physical factors of weight loss and malnutrition cannot be underestimated and this is reflected in a number of single patient case studies/reviews. Although they cannot be used as a general guide to the effects of anorexia, they do provide examples of potentially ‘extreme’ effects of EDs. Dhoble et al. (2008) presented a man with anorexia (14.1 BMI) who was hospitalised with a number of heart related complaints brought on by malnutrition. Shapiro et al. (2014) presented a 20-year-old male who had significant weight loss, 49% of his ideal body weight. His weight loss/malnutrition had caused heart problems (pericardial tamponade, excessive fluid around the heart), hepatitis (inflammation of the liver), and anaemia. He also encountered cortical atrophy (brain shrinkage) which affected his cognitive processing, whereby upon weight gain his condition improved. Cazzuffi et al.’s (2010) subject, had heart, liver and bone marrow issues when presenting to an ED unit, although he had first been sent to a gastroenterology unit for his weight loss. Alhanna et al. (2012) studied a 23-year-old man with a four-year history of anorexia, bouts of treatment and relapse who had seen his BMI fluctuate between 11.8 and 16.8, who developed a severe lung infection (with TB like symptoms), which resulted in his hospitalisation, brought on by fasting. The authors noted that the location and presentation of the infection within the lungs was consistent with other studies, although they did not specify which they were.

As well as these single patient case studies, the study by Sabel et al. (2014) looked at the medical data from patient notes in an ED unit over a period of four years. The study’s sample included 14 men who had all engaged in inpatient treatment. Their findings overlapped with some of the preceding case studies, but they also reported low vitamin D levels in almost 65% of the sample. This was reflected in three men having osteopenia and
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2.4.6 - PSYCHOLOGICAL FACTORS

To date, studies have rarely examined the psychological impact of EDs among men, and those that have noted the similarities between men and women regarding loss of quality of life (Mitchison and Mond, 2015).

2.4.6.1 - Self-Harm

In a study undertaken by Claes et al. (2012a) the authors examined male ED patients, their psychopathological and personality features and Non-Suicidal Self-Harming Behaviour (NSSI). NSSI, for the purpose of Claes et al.’s (2012a) study, was classified as cutting, burning or carving the skin. Claes et al. (2012a) had a sample of 130 men, all ED patients at a Barcelona hospital (anorexia N=27, bulimia N=44, EDNOS N=59). In total 27 of the men (21%) reported NSSI, six of the 27 men (4.61% of the total sample of 130) also reported an actual suicide attempt and their results were excluded from the study. Claes et al. (2012a) found that 18.5% of men diagnosed with anorexia had experienced NSSI. Additionally, 23.7% of men with bulimia and 11.9% of men with EDNOS also reported NSSI and they concluded no significant difference between the different eating disorders. Of the men who had engaged in NSSI behaviour, Claes et al. (2012a) reported that 66.7% believed their NSSI behaviour started with the advent of their eating disorder.

Claes et al. (2012a) compared their findings with those from an earlier US based study undertaken by Briere and Gil (1998) who concluded that 4% of the general population and 21% of their clinical sample of people who had self-mutilated and been victims of psychological and sexual abuse. In Claes et al.’s (2012a) study, 27 out of the 130 men (21%) who reported self-harm reported similar experiences to those in Briere and Gil’s (1998) study. Worryingly, Claes et al (2012a) found that of the 21 men diagnosed with anorexia whose information on NSSI they used, 14 (66%) reported that the NSSI behaviour developed simultaneously with their ED, four men stated it preceded their ED and three men reported it followed the ED. The men who participated in Claes et al.’s (2012a) study, and who self-harmed reported,
being more confused in recognizing and responding to their emotional states and reported greater feelings of inadequacy, insecurity, worthlessness and lack of control over one’s life. (p. 337)

Claes et al. (2012a) also found higher levels of impulse behaviour to control problems and more affective symptoms, such as general and phobic anxiety, depression and hostility in the males who engaged in self-harm as opposed to those who did not.

2.4.6.2 - Decision Making and Psychological Traits

When reviewing the literature, only three studies focusing on the decision-making processes of people with EDs were found. All of the studies were undertaken by Tchanturia et al. (2007; 2012; 2013), the first being a female only study (Tchanturia et al., 2007); the second one including males and the third focusing on men. In the second study Tchanturia et al. (2012) used the Iowa Gambling Task, a psychological task thought to simulate real-life decision-making, to examine the decision making of people diagnosed with EDs. The study found that impaired decision making is present in male and female patients diagnosed with anorexia as opposed to healthy controls. However, the study showed that men with anorexia showed much higher levels of impulsivity than their female counterparts and those in the control group, reaffirming the findings of Claes et al. (2012a). The third study by Tchanturia et al. (2013), specifically focusing on males, found once again impaired decision making; and clarifying this was not due to somatic symptoms and therefore linked clinical severity, but emanating from cognitive processes as in other psychiatric groups. This finding is extremely interesting as it shows cognitive functioning to be impaired at potentially any stage of anorexia.

An Italian study carried out by Fassino et al. (2001) highlighted a number of personality traits which male and females with anorexia share. In temperament and characteristic tests Fassino et al. (2001) found people with anorexia had low self-directness scores. This is a personality trait which refers to a person’s ability to regulate and adapt their behaviour to the demands of a situation in order to achieve personally chosen goals and values. It also refers to a lack of will power. According to the authors, a low self-directness score is an indicator of a personality disorder, with males and females diagnosed with anorexia displaying an immature and self-striving personality. A study by Claes et al. (2012b), this time of males with a range of EDs, found similar results, as well as elevated levels of harm.
avoidance (excessive worrying, pessimism, shyness, being fearful and doubtfulness) compared to healthy controls.

Fassino et al. (2001) went on to suggest that men with anorexia differ from women with anorexia, as they are more anti-social and are more likely to have an explosive personality than their female counterparts. Men also lack the pseudo-compliance, false generosity towards others and cooperation which is often seen in women with anorexia (Fassino et al., 2001). These latter findings were also found by Núñez-Navarro et al. (2012), who reported males with anorexia scored lower in tests than females with anorexia, specifically in relation to harm avoidance, reward dependence and cooperativeness. Núñez-Navarro et al. (2012) speculate that this perhaps relates more to gender differences in general rather than anorexia.

Raevuori et al. (2008) carried out a study based in Finland examining men with anorexia who had a twin. They found men with anorexia had a high number of obsessive compulsive traits compared to those who do not have anorexia. They also added that a number of the twins they interviewed who had not succumbed to anorexia, experienced mood and/or anxiety disorders and symptoms of muscle dysmorphia, the latter trait often being seen in men with anorexia. Raevuori et al. (2009) found anorexia was accompanied with significant psychiatric co-morbidity (more than one mental illness), reiterating the earlier findings of a study carried out by Bramon-Bosch et al. (2000). In Bramon-Bosch et al.’s study (2000), suicidal behaviour amongst their male sample (50%) occurred more frequently than their female counterparts (23%). However, this is in contrast to the findings of Raevuori et al. (2009) and Gueguen et al. (2012) who found women with anorexia were more likely to have attempted to take their own life, indicating that further study with regard to this topic area is needed. The study of Mitchell et al. (2014) highlighted that whilst depression was commonly linked with EDs, levels of externalising and phobias were also heightened, concluding that people with EDs were strongly associated with worry, rumination and negative affect (emotions such as: anger, contempt, disgust, guilt, fear and nervousness).
2.4.7 - SEX AND RELATIONSHIPS

Aspects from sexual activity to sexual preference have continued to be investigated, from both a psychological and biological perspective, as the studies used in the following section show.

2.4.7.1 - The Relationship Between Weight, Stress and Sex

The links between weight, stress and sex were initially demonstrated unequivocally by Keys et al. (1950) (see introductory chapter). Regardless of the theoretical lens used to explore sexuality and its relationship to anorexia, many studies (Bramon-Bosch et al., 2000; Fassino et al., 2001; Crisp et al., 2006; Lindblad, 2006; Mehler et al., 2008; Agalusca et al., 2012; Brown and Keel, 2012; Malik et al., 2014) have made some form of comment in relation to the relationship between these two phenomena. Indeed, from a medical perspective, up until the latest publication of the Diagnostic and Statistical Manual (DSM) V (2013), amenorrhoea in menarcheal females was used as criteria in the classification of anorexia. Of the studies identified for this review, Agalusca et al. (2012) highlighted the biological impact of weight loss and sexual hormones, reporting both males and females have decreased sexual hormones due to lower weight, leading to a loss of interest and physical functioning in sexual activity. Mehler et al. (2008) found testosterone levels in men with anorexia and EDNOS were significantly below the norm of a healthy male. The implication of this is duplicitous, as low testosterone impacting on sexual drive also affects bone (re)growth, leading Mehler et al. (2008) to conclude that osteoporosis in males is a much under reported complication of eating disorders, which is more severe in men than in women with the same illness. Mehler et al. (2008) also warned that the duration of the illness and low weight increase the risk of osteoporosis. While the studies undertaken by Agalusca et al. (2012) and Mehler et al. (2008) focused on the physiological aspects of EDs, and in particular anorexia, other studies have focused on the psychological/behavioural aspects associated with sexuality.

2.4.7.2 - Relationships and Eating Disorders

Lindblad (2006) found men with anorexia to have a lower inclination to form close relationships or become a father. Mehler et al. (2008) reported that 78.6% of their sample were single, a fact Button et al., (2008) also commented upon. Gueguen et al., (2012) also...
concluded that men with anorexia seemed less likely to be involved in “friendly and romantic relationships” (p. 542). Interestingly, Brown and Keel (2012) concluded that being in a relationship was a protective factor for disordered eating, although this study focused on homosexual men. Brown and Keele’s (2015) later publications concluded that single, gay/bisexual men were more likely to engage in restrictive eating practices, thereby fulfilling objectification theory in gay society. Interestingly they concluded that objectification theory did apply to heterosexual men not in a relationship. Positive relationship satisfaction was seen to be a factor in the reduction or absence of ED behaviours. However, not all relationships are positive. Cazzuffi et al.’s (2010) case study highlighted that the subject felt his ED behaviours started after “his girlfriend, affected by anorexia nervosa, used to tease him about being overweight, although he was normal,” (p. 1) this resulted in him taking up sports to lose weight.

Fassino et al. (2001) suggested there are two psychopathologic areas affecting men with eating disorders; the first involving sexual problems and the second personality traits (the latter having been discussed in the decision-making section of this chapter (2.4.6.2). With regard to sexual problems, loss of libido, femininity increasing the risk of dieting and issues of sexuality were identified as problematic, with the absence of sexual initiative being more frequent in men with anorexia than women. Crisp et al. (2006) found that men who were sexually active before their illness had a better prognosis than those who were not active, a finding replicated by Gueguen et al., (2012). Crisp et al.’s (2006) findings support earlier work undertaken by Herzog et al. (1984), who found higher numbers of men with anorexia to have not been sexually active before their illness, as opposed to their female counterparts. Fassino et al. (2001) also concluded, in terms of developing anorexia, sexual orientation was a risk factor in men. However, Fassino et al.’s (2001) sample included patients within an ED unit in Italy, with 20% of the men being homosexual; this being much higher than the accepted 4% of the general population being homosexual.

The case study by Manejias Parke et al. (2008) may be missed by many academics due to the size and age of the participant. What the authors do show, which is important to my research project, is the human tragedy of eating disorders and the impact upon daily life. Their subject was a 72-year-old man with a 20+ year history of food preoccupation/eating disorders. The rituals and beliefs he had put in place, such as a refusal of water and a fruit
only diet, had led to the breakdown of his marriage. Many of the studies reported in this review are quantitative, focusing on the presentation of statistics, rather than the human cost to those diagnosed with EDs, their family and friends.

2.4.7.3 - Gender Identity, Homosexuality and Sexual Identity

Gender identity issues have been identified as one of the potential triggers for anorexia, which in turn reduces and stops sexual functioning and thoughts, commonly rendering the person with the illness asexual. Crisp et al. (2006) suggested a common finding in their clinics was a “panic about possible homosexuality prompting anorexia nervosa as a defence” (p. 166). Lindblad et al.’s (2006) study concluded men with anorexia have lower inclinations to form close relationships, have sexual identity problems and asexuality. Focused interviews by Bassett (2002) indicated that half of the sample (4 men) indicated unspecified sexual issues, which had not been picked up when completing the appropriate questionnaire.

Bramon-Bosch et al. (2000) reported homosexuality among male patients being eight times higher than their female counterparts. The prevalence of eating disorders in homosexual men is greater than in their heterosexual counterparts (Feldman and Meyer, 2007). In a male specific study, Russell and Keel (2002) found that homosexual men had greater body dissatisfaction and higher levels of anorexic and bulimic symptoms than heterosexual men. They argue this is the case as, in the homosexual community, men are under much more pressure to look good than in the heterosexual community. The question of gender identity and eating disorders was the focus of Winston et al.’s (2004) study, it was suggested that anorexia may be more prevalent than initially identified within this community.

2.4.8 - SIMILAR RESEARCH STUDIES

Many hours were spent searching the various academic databases, ED journals and randomly searching the internet, but no studies directly comparable to this study were found. Whilst some of the studies identified above, such as Cooperman (2000), offer a narrow section of lived experiences within a general review, none of the studies have focused solely upon men’s lived experiences of having an ED outside of the clinical or
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with the focus on understanding how young men (16-25) recognise their ED and their initial impressions of primary care. The sample consisted of 10 men recruited from patient organisations, healthcare practitioners, social media and snowball sampling (asking the men recruited for further leads). The sample had an average age of 20 years and 4 months. It is an extremely important study, as it is both a qualitative study focusing on men and one that seeks their opinions of what impacts on their help-seeking behaviour. However, my study goes further than both Button and Warren (2001) and Räisänen and Hunt (2014) in terms of the depth of questioning, with a focus on exploring how an ED, outside of the clinical environment, impact on the lives of men.

### 2.5 – LIMITATIONS OF THE RESEARCH REVIEWED

The role of research is to investigate or try to answer a question and provide a path for future researchers to replicate, emulate and, if necessary, challenge findings. To achieve this, it is vital that researchers evaluate the strengths and the limitations of their work. Likewise, when undertaking a review of the literature prior to engaging in research there needs to be a critical evaluation of the papers under review. Some of the studies in this review have, for varying reasons, no examination of short comings, some use a mere sentence to say how future researchers could improve upon the original process, while other researchers are more forthcoming, candidly examining their studies. Broadly speaking the limitations of the research used in this review falls into two categories, sampling and study design: stemming from each are a number of sub categories.

#### 2.5.1 - SAMPLING LIMITATIONS

**2.5.1.1 - Sample Size**

The most common limitation reported by the authors of the studies reviewed (see Table 3 on the following page) is the size of the sample used within their research. As a high number of the studies in this review are quantitative, and as such need large sample sizes to improve the reliability of their results, this is concerning. It is no surprise with the nature of eating disorders in men that a number of the studies reviewed highlighted sample size as their Achilles heel. Lindblad et al. (2006) encapsulated this when they stated that their
sample size of 61 subjects “limits the possibilities of statistical testing of hypotheses” (p. 665), yet they follow this up by concluding that their sample was “one of the largest groups of male anorectics referred to in the literature” (p. 665). Mangweth et al. (2003) acknowledged their sample size was “modest” (p. 105), due to the rarity of male eating disorders. Table 3 (following page) shows the studies within this review that highlighted sample size, specifically the number of people with an ED, as a limitation.
Table 3 - Studies which Highlighted Sample Size as an Issue

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Sample Breakdown</th>
<th>Sample Size</th>
<th>Methodology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bassett (2002)</td>
<td>8 Men with anorexia</td>
<td>8</td>
<td>Mixed</td>
</tr>
<tr>
<td>Bramon-Bosch et al. (2000)</td>
<td>10 Men with anorexia, 15 Men with bulimia, 5 Men EDNOS, 30 Females with same</td>
<td>60</td>
<td>Quantitative</td>
</tr>
<tr>
<td></td>
<td>diagnosis as males</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Claes et al. (2012)</td>
<td>27 Men with anorexia, 44 Men with bulimia, 59 Men with EDNOS</td>
<td>130</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Fassino, et al. (2001)</td>
<td>15 Men, 50 Women</td>
<td>65</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Fernández-Aranda, et al.  (2004)</td>
<td>7 Men with anorexia, 13 Men with bulimia, 7 Females with anorexia, 13 Females</td>
<td>40</td>
<td>Quantitative</td>
</tr>
<tr>
<td></td>
<td>with bulimia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tchanturia et al. (2013)</td>
<td>11 Men with anorexia, 28 Male controls</td>
<td>39</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Lindblad et al. (2006)</td>
<td>61 Men</td>
<td>61</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Mangweth, et al. (2003)</td>
<td>17 Men with anorexia, 10 Men with bulimia, 42 Male controls</td>
<td>74</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Murray, et al. (2012)</td>
<td>24 Men with anorexia, 21 Men with muscle dysmorphia, 30 Male controls</td>
<td>75</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Raevuori, et al. (2009)</td>
<td>20 Men with Eating Disorders, 11 siblings</td>
<td>33</td>
<td>Mixed</td>
</tr>
<tr>
<td>Scagliusi, et al. (2009)</td>
<td>7 Men with anorexia, 10 Men with bulimia, 30 Females with anorexia, 20 Females</td>
<td>67</td>
<td>Quantitative</td>
</tr>
<tr>
<td></td>
<td>with bulimia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Striegel-Moore, et al. (2009)</td>
<td>3,714 women and 1,808 men (General Population)</td>
<td>5522</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Strober, et al. (2001)</td>
<td>29 Men with anorexia, 323 Females with anorexia, 727 Relatives</td>
<td>1079</td>
<td>Quantitative</td>
</tr>
</tbody>
</table>

2.5.1.2 - Sample Demographics

Leading on from sample size, the demographic make-up of a sample is another potential limitation, whether the following are limitations is open to discussion, but they were identified as such by the authors, who generally cautioned others from generalising their
results due to the narrow range of their sample. Scaglìusi et al. (2009), Striegel-Moore et al. (2009), Brown and Keel’s (2012), Grossbard et al.’s (2012) and Dakanalis et al.’s (2014), highlighted a limited demographic range within their samples; these range from nationality and race, to educational attainment. Button et al. (2008) identified demographics as a potential limitation as their sample came from only one NHS trust, although unlike other studies (discussed further in the following Section 2.5.1.3) they did not identify a clinical sample as a potential limitation. Bassett (2002) concluded that only one man in the study was severely underweight which may limit findings, whilst Räisänen and Hunt (2014) suggested that the oldest participant in their sample, being 25, was a potential limitation, the latter perhaps not reflecting the longevity of the illness.

2.5.1.3 - Clinical Sample

Samples in a number of studies were drawn from in and/or out patients within eating disorder treatment centres. A number of authors were keen to draw their readers attention to this and the risk of generalisations (Strober et al., 2001; Lindblad, et al., 2006; Mehler et al., 2008; Gueguen et al., 2012; Núñez-Navarro et al., 2012; Murray et al., 2014). Applying findings to a wider population based upon a clinical sample of those who, theoretically, are exhibiting more extreme symptoms is not helpful in addressing the needs of the majority and may compromise the opportunity for primary prevention.

2.5.1.4 - Non-Clinical Sample

In the following three studies, non-clinical examples were seen as problematic. Smith et al.’s (2010) sample only consisted of University Students, so whilst it was non-clinical, it was also non-representative of the male population and thus compromised generalisability. Lavender and Anderson (2010) surprisingly described their “non-treatment seeking” sample as a limitation and that further study needs to take place using samples consisting of men with EDs. This appears to be an ambiguous statement, leaving the reader to question if those they included had a self-diagnosed ED, and chose not to seek help, or if there was no evidence, diagnosed or otherwise, of an existent ED. Likewise, Brown and Keel’s (2012) issue with a non-clinical sample was that it included men who had no formal diagnosis of an ED. If this is the case, then a question within the survey asking people if
they had a formal diagnosis would have given an indication as to the number of men within the sample who had no diagnosis, but who had an issue with eating.

2.5.1.5 - Data Collection

The actual way in which data is collected can be fraught with problems. For example, allowing participants to self-report was a common limitation in some of the studies. Lavender and Anderson, (2010) identified this stemming from their use of questionnaires. They argued that questionnaires resulted in slightly higher scores in relation to binge eating, an issue also highlighted by an earlier study undertaken by Striegel-Moore, et al. (2009). The studies of Raevuori, et al. (2009), Smith, et al. (2010) and Núñez-Navarro, et al. (2012) also highlighted self-reporting as a limitation of their studies.

The issues of self-reporting are described by Grossbard et al. (2012), who candidly wrote that their findings should be “interpreted with caution” (p. 8) as their findings, based on self-report, may reflect “social desirability or demand characteristics” (p. 8). The highlighting of self-reporting being a limitation of study design is a paradox as, in the following section (2.5.1.5), Mitchell et al. (2012) highlighted a limitation of their study being that the interviewer’s opinion on what was important was reported, rather than emphasis given by the subjects. It would appear that whichever method used to gather data, there is the potential for limitation. From the evidence, self-report may be imbued with responses the participant believes the researcher wants to hear, or those that fit with the dominant socio-cultural context. However, researchers should not shy away from self-report, but rather accept that. Just as each participant will have an account of their story that is temporally anchored, each researcher will tell the same story differently, what Barthes (1977) refers to as ‘the death of the author’. For the qualitative researchers, it is important to promote transparency, allowing the reader insight into how meanings have been negotiated and ascribed, in particular social contexts. In achieving this, the reader is offered the opportunity to revise the text, thus adding to its constant growth, development and refinement (McAndrew, 2008).

2.5.1.6 - Study Design

Analysing the design of the study can provide a plethora of information to a researcher by identifying the strengths and weaknesses of differing methodologies. This is particularly...
pertinent in a topic area such as men’s EDs, where sample sizes are small as indicated previously in Section 2.5.1.1. It may be easier to change the design of a study to gain information to more accurately address the research questions, than it is to change a sample. Many of the changes identified below are small, yet the difference can alter the findings dramatically.

Mitchell et al. (2012) highlighted two issues with their data collection methods, the first was that participants were able to skip questions on the survey if certain answers were given, which meant that there was potential for information to be lost. In a similar vein, Murray, et al. (2012) noted that the Eating Disorders Examination Questionnaire (EDE-Q) they used had not been psychometrically validated, although they added that it had been used in other academic studies. The second issue for Mitchell et al. (2012), regarding the qualitative aspect of their study, was participants being asked to detail post-traumatic stress, some of them having had multiple experiences of this. Where the latter was evident, it was the researcher’s responsibility to select what he/she thought was the worst trauma which was then included in the results. This has the potential to significantly bias the findings and, in light of it being a qualitative study, somewhat loses the ‘voice’ of the participant, a major philosophical underpinning of this research paradigm. Continuing the theme of data gathering techniques, Claes et al. (2012a) reported that they failed to assess the frequency, severity and functionality of NSSI and only asked if a person had engaged in this behaviour. Although from a theoretical standpoint, Claes et al.’s (2012a) study being a quantitative study, the narrow parameters are understandable; it does perhaps highlight the need for more in-depth information gathering methods in research, particularly when it comes to severity and functionality of issues such as NSSI.

Perhaps more concerning is the recurring theme in this review of the lack of research information attesting to EDs in males. Mitchison et al. (2013) in their quantitative study reported that they were unable to find any secondary data to compare their results too. Although correct to highlight this, it may not be a problem with the study’s design per se but may serve as an indicator of a lack of research within this area and highlight the need for more academic interest. Similarly, Mehler et al. (2008) highlighted that a retrospective design had proved limited in examining Osteoporosis in males with eating disorders. The data that they had access to for some subjects did not include; personal histories,
An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

testosterone levels, calcium and vitamin D intake, all of which are important facets that need to be taken account of when researching this topic area. Núñez-Navarro, et al. (2012) also highlighted collecting retrospective data as a limitation.

The study undertaken by Grossbard et al. (2012) was the only study that highlighted having a cross-sectional design as being a limitation, reporting that a longitudinal design would have given a history of data points for a participant over a period of time. Whilst a number of the studies used a cross-sectional design, it is surprising that only Grossbard et al. (2012) raised it as a limitation given the longitudinal nature of EDs.

A number of other studies noted problems in design in terms of questions/areas investigated. Mangweth et al. (2003) highlighted that participants were not screened for other psychiatric disorders. Fernández-Aranda et al. (2004) bemoaned a lack of structured assessment of gender specific traits and participant follow up was not measured longitudinally using quantitative techniques. Gueguen et al. (2012) wrote that not investigating features associated with gender such as sexual orientation and excessive exercise was a limitation, whilst Grossbard et al. (2012) did not account for the athletic status of their subjects.

2.5.1.7 - Non-Blind Studies

Three of the studies, Strober, et al. (2001), Mehler, et al. (2008) and Raevuori, et al. (2008), all reported that their findings could in some way be limited as they were unable to conduct completely blind studies, meaning that those participating in the studies knew what was being examined and such knowledge could influence their responses. A blind study is perhaps the best way to gather information as it reduces the influence of positive or negative bias from the participants. Strober et al. (2001) highlighted telephone interviews as a possible limitation, as the remoteness allows the participant to potentially disclose less. As a method, Strober et al. (2001) cited a number of studies to validate this method in mental health research. It is important to note in the design and operation of my study there will be a reliance upon remote interview techniques (telephone and messaging), and it could be argued that remoteness may increase a person’s anonymity and ability to disclose information. Novick (2008, p. 397) concluded, telephones may allow respondents to disclose sensitive information more freely. The use of remote data collection will be discussed further in Chapter 3 Methodology.
The above limitations give some insights into the rigour of the studies reviewed, and how at times this becomes compromised. The point being made in this section is that no matter who is carrying out the research or whatever the subject matter, as the study progresses shortfalls become apparent. However, when setting out to do research the researcher does have responsibility to be cognisant of such limitations and learn from these in an attempt to ensure their study avoids such problems.

2.6 – LITERATURE REVIEW CONCLUSIONS

2.6.1 - INTERPRETING THE REVIEW FINDINGS

The most obvious finding from the preceding literature review is that there were no studies comparable to this one, and those with similarities in design were broadly focused on different areas or had different samples. This therefore provides academic justification for this study’s existence and advancement of the literature within the areas of study. In terms of qualitative research, there is a dearth of studies, with approximately 1 in 4 of the studies (27.9%) using qualitative methods. 17 studies used qualitative methods and a further four (6.6%) used mixed methods, whilst 40 (65.6%) of the studies identified in the review used quantitative methods only. From the point of view of the legitimacy of this study it is a compelling argument to say it is needed, solely because it is a qualitative study with a unique focus.

Overall, this literature review has highlighted the need to provide a platform for men to talk about how their ED has affected their life, as, to date, the literature tells us very little. Only Cooperman (2000) and Räisänen and Hunt (2014) in essence have asked men about their perspectives, with Cooperman (2000) only achieving this in part of her study, whilst Räisänen and Hunt’s (2014) study focused on their treatment. Three of the quantitative studies, Tong et al. (2005), Manejias Parke et al. (2008) and Younis and Ali (2012) were case studies, reporting on treatment and conditions, but information gathered was from medical sources such as those gathered from patient notes.

As expected, there are no smoking guns and the many studies based on quantitative methodology offer areas for further development, which I would argue needs to be undertaken using at least mixed methods. The psychological effects of EDs pose many

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interesting questions. For example, the statistics show men with anorexia are more impulsive than their female counterparts, but the possible underpinning reasons for this need further explanation. Likewise, the sexual inactivity of men diagnosed with anorexia, while factual from a statistical standpoint, will only be fully understood from their personal perspectives. The human stories are missing, and in my opinion the best way to move research forward is to explore how illness affects day to day life. As in my own experience of the illness, it helps the person with the illness as well as enabling the wider community to gain a better insight, the later point being evidenced by Morris (2006) writing about stigma discussed in Chapter 1.

2.6.2 - ‘MR POTATO HEAD’ – THE JOHN DOE MALE ANOREXIC

In terms of other findings, we can build up a “photo fit” of a typical male with anorexia, which may in some ways be used as a guide to create a stereotypical anorexic man. He is between 15-20 years old at the age of onset of the illness; however, it is unclear if this is the age he is classified by the medical community or the age he identifies when his behaviour started. He was at some point before onset overweight, and his anorexic goal is to lose weight to become more “toned/muscular/athletic”, as opposed to a female whose goal is to achieve thinness. As well as restricting food, his favoured method of ridding himself of calories is by way of excessive exercise, although rarer, other forms of purging may also be used with vomiting being much more favoured than laxative abuse.

Within his family background it is likely that there is a history of weight or/and mental health problems. Although a high statistical number of men with anorexia are homosexual, four out of five men with anorexia are actually heterosexual. Although heterosexual, he is likely to have problems with his ability to form relationships (platonic and sexual) and as a result is likely to be sexually inexperienced, although his prognosis is much better if before onset he has been sexually active.

In terms of his psychological profile the evidence from available research is a little “cloudier”. In terms of his own feelings about himself, words such as “insecure”, “worthless” and “inadequate” are common, as well as a belief that he lacks control in his life. The possibility of co-morbidity with another mental illness is likely. In terms of psychological traits Obsessive Compulsive Disorder (OCD) like tendencies, difficulty with
decision making, impulsivity and/or immaturity are likely to manifest. He will show more anti-social behaviour than his female counterpart in terms of lower levels of approval seeking and more bouts of rage, as well as being less compliant and cooperative.

2.6.3 - GOING BACK TO 2000

This literature review began in the year 2000, of the two studies from that year, Cooperman’s (2000) study was particularly important, as it was commissioned by the then Eating Disorders Association charity, now known as Beat. Cooperman (2000) highlighted three findings,

not enough is being done at present to address the needs of men with eating disorders. Whilst there is considerable overlap between men and women in the causes of their eating disorders, the treatment and outcomes, much is based on small studies and there has been little exploration of the specific treatment needs of men. There are clear problems with access to services for men. (Cooperman, 2000 p. 2)

However, since Cooperman reported her findings, there have been no further studies commissioned by the charity on eating disorders in men. From the literature examined in this review, it would appear 17 years after publication, that if her study was replicated today, her first and second findings would still be valid. This is a sad indictment regarding the level of interest in men’s EDs, and perhaps unconsciously reinforces the belief of it being a ‘woman’s illness’. The voice of men with eating disorders is seldom heard in academia, and without the experiences and stories bringing the existing body of knowledge to life, the rate of change is likely to be slow. The literature review shows that although many of the studies have “found” information, there has been very little critical appraisal of findings in terms of identifying what needs to be changed and how, thus indicating the need for studies such as this to compliment and further what already exists.

The evidence provided within this literature review justifies the assertion within Chapter 1’s introduction as to the need for qualitative investigation into the experiences of men with EDs. The following chapter sets out the methodology for this investigation, examining the philosophical beliefs behind the research methods used.
CHAPTER 3 - METHODOLOGY

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons
3.1 – AIM OF THE STUDY

To explore the lived experiences of men who have, or have had, an Eating Disorder in the form of anorexia or an a-typical variant (EDNOS).

3.2 – STUDY OBJECTIVES

- To explore the lived experiences of males with anorexia or an EDNOS, focusing on how the illness has affected their lives.
- To add to the body of knowledge on male anorexia and EDNOS by disseminating the findings of this study through publication in academic journals and conference presentation.
- To clearly identify avenues for further research regarding male EDs.

3.3 – IN THE STYLE OF RIESMAN - A REFLECTION ON CHOOSING IDEOLOGY AND METHODOLOGY

Before any study can be undertaken, the researcher must make clear their research position, enabling the reader to understand why certain methodological approaches were chosen in order to answer the research questions. Such transparency allows critical evaluation, as differing theoretical positions have their own strengths and weaknesses. There are a number of differing research ideologies which in recorded western civilisation can be traced back to classical Athens, and philosophers such as Plato, Aristotle and Socrates. Pursuing this Hellenistic theme, delving into research ideologies is akin to Heracles’ trial against the Lernaean Hydra, a beast, which for every head he cut off grew two more.

The social researcher is often faced with a scenario whereby the more they delve into methodology, the more differing approaches they find within each school. There are a myriad of competing ideologies, which contrast, overlap and generally decry all other ideologies. At a relatively early point in the research process I was able to identify that narrative interviews were likely to be the best means of collecting data in order to meet the aim of my study. An ideology such as Positivism was therefore ruled out at that point.
However, in documenting my thoughts throughout the research process, I realised from an early point I was veering towards qualitative methodology, my recorded thought processes being:

I think I want to use interviews, because after thinking about it and listening to the advice of my second supervisor it seems to be the best way to get information about men’s experiences of EDs. Initially I thought about using a questionnaire, but after our discussion I don’t think this will be adequate, if what I really want to know is about men’s experiences of living with an ED.

My initial thoughts above, in my opinion, did not show the rigour of an academic process where the researcher clearly states their beliefs about the nature of reality and carefully dismantles other approaches before finding their chosen path. In truth writing such a section was beneficial as it allowed me to refine and think about my understanding of research, even if it meant confronting a long-standing aversion to words ending in “ology”!

By explaining how, using a narrative approach, such as that used by Riessman (1990), the methodological journey unfolded and my own understanding (perhaps incorrectly to some) of the various schools of research ideology and methodology, the reader can at least make sense of the work presented. As a researcher, and perhaps from my business and teaching background, I believe that in terms of problem solving I am goal driven. I feel that I work better with a goal or target, and then work backwards looking at the best ways to achieve this. In teaching this was based around looking at what my students had to learn and then tailoring lessons to their needs and learning styles; in business my decisions are driven by the end users/market. In terms of this study, it meant knowing what I wanted to learn and what would be the best way of achieving this.

3.3.1 - THE CRUX

My understanding of ideology or to put it simply “what I believe in” is subjectivity, and not reality. In terms of reality I believe that some things are governed without human intervention, whilst others are governed by experiences and society, and my views on subjectivity are the crux of the matter. I believe that objectivity is important within research, but something which is very difficult to achieve. I do not believe that anything involving a human being can be objective. During my own therapy I have heard on
numerous occasions my therapists say they were non-judgemental and objective, yet their faces seemed to tell a different tale. I do not believe, no matter how professional you may try to be, that you can lock your thoughts and experiences away and be completely objective; I certainly was not during my teaching career in dealing with pupils who had previously verbally abused me or, for example, being able to leave my own health concerns at my classroom door. Whilst I believe that we should try to be as objective as possible, some level of subjectivity is innate in all research, no matter what the methodology; the story the researcher tells, how the audience interprets the information, as well as how it is presented, is totally subjective. This therefore puts my beliefs outside of the Positivist and Post Positivist schools. However, while social science may focus on perceptions and experiences, there is no reason why it should not be as scientifically robust as possible.

3.3.2 - EXAMINING POSITIVISM

Positivism in the sociological sense can be traced to Auguste Comte, who for many was the father of sociology. Comte’s background, as with many early sociologists, was in the traditional natural sciences, and it is no surprise that their beliefs were based around the traditional scientific viewpoint of research (which in essence is the positivist philosophy). Positivists believe research can only be valid if based around what can be objectively observed and classified, and that there is a single truth that can be measured and proved. Comte believed that sociology and sociologists should not be concerned with what is internal, such as meanings, motives, feelings and emotions, as these cannot be measured objectively (Haralambos and Holborn, 2008). The assumption in early Positivism was social phenomena could be measured and studied objectively. This mindset, and its limitations, has over time splintered and evolved into Post Positivism, a branch of the ideology still believing in the principle of an objective structured world, whilst accepting the need for a variety of methods to test variables (Gephart, 1999). In addition, post-positivists also recognise the notion of a researcher being able to study without their values or experiences interfering as being almost impossible, although this view has the caveat knowledge claims and generalisations can still be valid if they are supported by logic (Hustler and Goldbart, 2005).
Positivism assumes an objective world where scientific methods can measure, predict and explain relationships between variables (Gephart, 1999). The belief that social systems are structures and an extension of the natural world. These structures are independent of individuals and therefore able to be studied objectively (Livesey, 2006), is a tenet that I personally do not believe. Social structures are rigid, shaping how as individuals, we behave and interact. For example, laws govern behaviour. As a result of this, positivist study is generally concerned with observing the effects of structures on individuals to identify causes. In light of the above, positivist research is traditionally based on quantitative (measurable) methods with high levels of structure and control such as questionnaires/surveys. The collection of quantitative data is predicated on a high degree of measurability, validity and reliability, important maxims in positivist theory. This suggests data is collected in an objective or “clean” scientific manner without researcher contamination.

Whilst I believe in the need to be objective, I do not believe in the one-way relationship between structure and the individual, for example, why if we are governed by the same laws do we have differing opinions on them? Rejecting Positivism, leaves two other ideologies, Interpretivism and Critical Theory.

3.3.3 - CRITICAL THEORY

There are many different branches associated with Critical Theory, but the most popular stem from the Frankfurt School and then from one of its’ post World War 2 students, Jürgen Habermas who broke with the school, and its director Max Horkheimer, over its post war direction (Held, 2004). Horkheimer was credited with putting down on paper what makes Critical Theory different to other forms of research in his essay ‘Traditional and Critical Theory’ originally published in 1937. Horkheimer (1972) wrote that the aim of ‘Critical Theory’ is to critique and change society, whereas traditional theory, Positivism and Interpretivism, are concerned only with understanding and explaining. This appears to be the main difference between the differing methodologies; Critical Research is driven towards emancipation, whereas Positivism and Interpretivism are focused on description and understanding (Brooke, 2002).
Although over time Critical Research has diversified, there is still a general consensus that the aim of Critical Research is,

To lay the foundation for an exploration in an interdisciplinary research context, of questions concerning the conditions, which make possible the reproduction and transformation of society, the meaning of culture, and the relation between the individual society and nature. (Held, 2004 p. 16)

Haralambos and Holborn, (2008) suggest “Critical Social Science embraces all those approaches in sociology which aim to be critical of society in order to facilitate social change” (p. 804). For some, Critical Research differs in that it acknowledges critiques as an integral part of the research process (Harvey, 1990). These modern definitions show that although Critical Theory has evolved and splintered, the tenets of Horkheimer’s (1937) theory are still central to any critical research process today. Critical Theory, such as Interpretivism, rejects the Positivist notion that research has to be objective, reasoning that as members of the human race we are unable to shed our beliefs, values and experiences like a coat to undertake research in a completely objective manner.

Critical Theory is perhaps the least accepted research methodology of the three discussed above. Oates (2007) suggested Interpretivist work is often discriminated against by those who control academic journals, the reason being such people have leanings towards Positivism. Critical Theory is even further removed from Positivism than Interpretivism and it is easy to understand why it is the least accepted. Furthermore, the aim of Critical Research, from its political Marxist roots, is to work towards empowerment of the individual, and can be problematic and challenging for the establishment concerned with keeping the status quo. Held (2004) suggested that when the Frankfurt School moved to the United States their research was toned down because they found it difficult to attract sponsorship. This is no surprise when people are looking at and questioning society and its institutions; organisations that, in the main, finance research are likely to react negatively, yet doing this goes away from what is an idealistic theory.

However, Wexler (1991) argued that Critical Theory as a form of social research has gone backwards from its original ideals. As with Held’s (2004) critique of the Frankfurt School’s ‘toning down’, Wexler (1991) suggested the drive for academic recognition had created a social research of academic talk, with little or no social action or emancipation.
He wrote that Critical Theory had “escape[d] into elaborately sublimated fantasies as theory, discourse and text” (Wexler, 1991, p. 243).

Initially, I leaned towards the ideals of Critical Theory as a theoretical base for my study, however I stepped away from this standpoint. I have been highly influenced in my desire to understand and formulate my ideas, by Professor Jordan Peterson’s (University of Toronto) online lectures and discussions. Professor Peterson’s lectures focused on the nature of psychology, free speech/compelled speech and direction of academia away from spaces to discuss and challenge ideas, to ones where contrary thought is shut down. I have also been fortunate to read The Gulag Archipelago (Solzhenitsyn, 2003) and by chance watch Angus McQueen’s (2000) documentary Gulag. These sources helped to influence my thinking away from Critical Theory, originally brought to life out of Marxism which has morphed into the Post Modernism of today (Peterson et al., 2017). However, I believe its notions of oppression and blame seeking promotes intolerance, division and limits free speech. Ironically a friend who is a Christian asked me to go to bible classes with him and whilst I do not share his faith, the problems people of his faith are having in society further reinforced my negative attitude towards modern Critical Theory.

The original ideals of equality within Marxism may be laudable, but we do not live in an ideal world, we rely upon the subjectivity of human beings to implement and control the structures of society. The 20th Century graphically showed the failings of Marxist systems and I feel within our own current culture the rise of identity politics which stems from post modernism, negates the responsibility on the individual to be their best. Linking this to critical theory philosophy was something that I felt I could not do, even if my study was able to change the world for the better. The principle of trying to change “wrongs” for the better is helpful, but the political back story made me uneasy, especially when using narrative research. Fraser (2004) identifying herself as being influenced by feminism, critical theory and post modernism, wrote that many researchers who share her views “go to great lengths to qualify the interpretations that we make” (p 183). Whilst subjectivity is always going to be a legitimate question mark over qualitative research, with an overarching ethos for change (critical theory) and the pigeon holing of groups into oppressed and oppressors (post modernism), one must ask whose story is being told, even when the researcher goes to great lengths to qualify interpretations. I believe it is much
better to have a more restrained theoretical background, with the aim/s being to find things out from those who have knowledge through experience. I believe that when an aim is changed, as in critical research, then reasons are found to promote change even if it is not necessary; it is a self-fulfilling prophecy. This therefore guided my theoretical ideas towards the Interpretivist school.

In truth this was an exploratory study to gather experiences, and if in time it promotes change, it needs to be change for the benefit of all and not change for the sake of change or to be used for political point scoring. As such my study could never fall into the category of critical research. The Interpretivist school, where subjectivity is promoted through the gathering of opinions and emotions, has a more conservative measured approach which I feel is lacking in Critical Research, where there is an acceptance before research starts of a need to change.

3.3.4 - INTERPRETIVISM

Interpretivism is a school of thought, which is almost the polar opposite of Positivism especially in terms of the main ideology. This is articulated in the debate between objectivity and subjectivity, components at the core of each ideology. Positivists champion the collection of objective data and therefore reject the collection of internal beliefs as not being scientific. Interpretivists argue that objectiveness is unattainable, countering that no data can be completely objective, as at some point a researcher has had to formulate a question, choose a sample and, to some degree, choose how to analyse data, all tasks that reduced objectivity.

Interpretivism is based on the belief that sociology is the interpretation of social action. Social action cannot simply be measured, as it is impossible to derive the meaning or motives of actions from statistical data (Haralambos and Holborn, 2008). Interpretivism is more openly concerned with subjective meanings which relates to how individuals and members of society understand and make sense of social events and settings (Gephart, 1999). The German sociologist, Wilhelm Dilthey argued that, as “humans, we have the opportunity to delve much deeper than the more empirical and objective methods used by positivists” (Walliman, 2006).
Interpretivists argue that people in the same situation will interpret that situation differently and the same person may react in the same situation differently based upon previous experience (Braa and Vidgen, 1999). As a result Interpretivists, in order to collect the data they desire, often have to consult with their subjects through the use of open ended questioning. This “open-endedness” can be difficult to analyse as it relies upon the interpretation of the researcher. For positivists, this interpretation compromises the scientific value of research in terms of its validity and reliability. To summarise, Positivists look towards structures in society shaping individuals, Interpretivists look towards the individual shaping the structures.

If positivism, and by association quantitative research, is steeped in finding one truth, Interpretivist researchers using qualitative methods accept the notion of multiple realities; a person’s frame of reference can differ depending upon time and situation. Qualitative research is grounded in a philosophical position that deals with how people understand experience and interpret their world (Mason, 1996). Qualitative research has evolved from a variety of traditions, including ethnography, phenomenology, and social constructionism (Madill et al. 2000).

3.3.5 - COMPARISON OF RESEARCH PARADIGMS

Critics of positivism argue that the methods used strip the context from any meanings when relying on quantifiable data. In particular, concern is raised over excluding the respondents own meaning and understanding and thereby imposing their own meanings on the analysed data (Guba and Lincoln, 1995). Positivists see the world very differently to Interpretivists and Critical Researchers, in that they see the world as independent from the mental thought processes of the individual. Oates (2007) is quite clear in writing that positivists believe “what we can learn about the world does not depend on who we are or how we personally have experienced it” (p. 284). Whilst at a traditional scientific level this may be correct, at a social science level the world and its structures go on despite what an individual does, although when individuals form groups they can begin to be able to influence and affect the world. This belief of the world being governed by regularity and rules may well be the case in the natural sciences examining phenomenon such as forces or chemical reactions. However, it is difficult to study the perspectives of men with EDs,
without accepting that social structures and their individual experiences of these contribute to their own individual thought processes.

Positivism also differs from Interpretivism and Critical Theory in the actual goals of research. Positivist research is planned and executed towards a specific goal, that of either disproving or proving a hypothesis. The need to measure and be objective reduces the variables in any study, narrowing the scope to its component parts. For example, does $X$ have an effect on $Y$? This approach is completely impractical for this study as the aim is to capture the men’s stories of having an eating disorder and how it has impacted on their lives. Positivism is at odds with my ontological beliefs, which encompass subjectivism and the existence of multiple realities, in this instance the shared experiences of the men’s stories will differ according to their life experiences.

### 3.3.6 - CHOSEN RESEARCH IDEOLOGY

This research is based in the philosophy/ideology of Interpretivism. In truth this is an exploratory study looking at a wide range of experiences and it does not have the capacity to promote actual change (excluding critical theory), but rather to act as a catalyst to ensure increased insight and understanding and for future studies to build on. At the onset of this research, and putting my own experiences and opinions as far into the background as possible, there was no way of knowing if the men’s stories would call for further research, change or be a voice for the status quo.

A Positivist approach to this research project was not a viable option, as it would be inappropriate to ask an individual for an opinion, thought or feeling using a Likert scale. For this reason alone, a positive methodology was excluded. Furthermore, my subjectivity as the researcher was a limitation, within a positivist sphere. My own life experiences of an eating disorder have played a huge part in the creation, focus and direction of the study. To expect me to “don a white coat” and remove my feelings is, I believe, nigh on impossible, and whilst it may not affect my professionalism, it would still be a question mark hanging over the study.

Peterson (2015) in a podcast titled “Religion, Myth, Science, Truth - An Evening of Darwinian Thought” said,
If you’re studying information, you cannot study it objectively; precisely because as you study the information you get informed and that changes you. And so, the problem with studying this sort of thing is you cannot study it without being changed because if you’re not changed by studying it, you’re not studying it!

Whilst the frequent references to change may alarm, my interpretation of his meaning is that objectivity does not exist, because our experiences constantly change and therefore the way we interpret things changes. This therefore leaves the Interpretivist methodology as the one most appropriate to be used in this study, allowing for a subjective narrative investigation which is able to delve into feelings, emotions and perceptions of the participants and report these using underlying themes.

### 3.4 – RESEARCH DESIGN

#### 3.4.1 - EXPLORING THE NARRATIVE

The aim of this exploratory study was to collect men’s experiences, and it was inconceivable to use a totally structured approach as this may have missed experiences which could have been important to the men. Morris (2006) wrote that allowing people contact with people with mental health problems was a way in which stigma could be challenged and public knowledge increased. Without having the person physically in a room sharing their story, the best way to do this seemed to be to record this in a different format, for example through research which gives voice to its participants. Seeking to examine experiences and perceptions puts data collection into the qualitative school and as such, listening to men’s stories or narrative interviews (Section 1.4.5.1) were chosen as the best way to gather personal experiences.

There are many ways to define narrative, at its most simplistic level the Oxford Reference Dictionary (1990) defines a narrative as a “spoken or written account of connected events in order of happening” (p557). Etherington’s (2011) definition of a narrative approach is very similar, as the gathering of peoples’ stories as told by them. Fraser (2004) wrote that as human beings we use “narratives to express emotions and convey beliefs about how things should be” (p180). This perhaps is the crux of why a narrative approach to collecting information in this study was used, in that it allowed men who had direct experience of anorexia or a-typical anorexia/EDNOS to express their own stories in their
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own words. Fraser (2004) suggested our culture is created through stories, and this in itself is apt, as what is Bourdieu’s (1986) Forms of Capital if not the stories that we tell ourselves and that shape us?

3.4.2 - REJECTED RESEARCH METHODS

There were other qualitative research approaches which could have been chosen for this project, but I did not feel they were as suitable as the narrative approach in obtaining the depth of understanding of how anorexia and EDNOS had impacted on the men’s lives from their perspective, and what meanings they attributed to related life events.

3.4.2.1 - Ethnography

As a method of gathering information I found Ethnography fascinating. It is the study of interactions, behaviours and perceptions of particular groups and was discounted because the only things guaranteed that the participants shared before recruitment was their gender and an ED. They could have been from different socio-economic backgrounds, different races and have different sexualities which would have made an ethnographic study difficult. Given the nature of Ethnography, information is collected by longitudinal observation of participants’ in their daily lives, this would have been impossible on a sample of people with anorexia and/or EDNOS, unless they were within an inpatient or day care unit. A further difficulty would have been getting a large enough sample to analyse. One of the main concerns is that Ethnography relies upon the researcher’s voice to tell the story, with my own history of having an ED, I felt that this would compromise the ownership of the men’s stories. There was also the possibility if doing an ethnographical study of male EDs of “going native” given the closeness in time of my own illness to the research; I doubt an ethics panel would have approved such a venture.

3.4.2.2 - Phenomenology

Phenomenology is the study of phenomena; I personally felt the breadth of experience which this study aimed to encapsulate was too wide to fall into the study of a phenomenon. Robinson et al. (2012) was one of the three studies identified within the literature as similar to this study (qualitative, gathering experiences/opinions) adopted a Phenomenological approach. However, the study’s sole focus was on experiences around

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treatment, unlike this study which asked amongst other things about background, treatment and work experience.

A Phenomenological approach relies upon the researcher being able to detach (bracket) themselves from their own feelings when collecting and analysing data regarding a participant’s experiences of a particular phenomenon (Somekh and Lewin, 2005). However, the idea of bracketing comes from Hursserlian phenomenology, later revised by Heidegger, who acknowledged the challenges in trying to distance oneself as a researcher from those who are being researched (Jack & Wibberley, 2013). As previously stated I do not believe that total objectivity exists and therefore even if a single phenomenon was studied, I would not be comfortable with this approach as I feel it is impossible to be fully detached, particularly in light of my own previous experiences. With the difference in academic opinion over the nature of subjectivity, particularly within Phenomenology, this equally chastens the approach as people can question the methodology.

3.4.2.3 - Grounded Theory

Grounded Theory was another qualitative research technique which was discounted. As as a novice researcher I did not feel I had the skills or experience to undertake such a process, nor, and perhaps more importantly, was this research based around generating a specific research question. Using a Grounded Theoretical approach would also have been very difficult in terms of sampling, due the potential small number of participants and the lack of control of participant demographics and the need for discriminate sampling (repeating interviews with a new sample to test theory) (Somekh and Lewin, 2005). A small sample, as was the case in this research, would have made a trying to create legitimate and testable theory impossible.

In addition, ethnography, phenomenology and grounded theory all require data to be fragmented before reconstruction, reducing, in this instance life stories, and for me compromising the voice of the participant.
3.4.3 - SAMPLE

3.4.3.1 - Number of participants

This was a qualitative study using narrative interviews (see Section 1.4.5.1) to gather information and as such there was no fixed upper sample size. The focus for this type of study was on the uniqueness of each individual story and the ability to gather rich data in order to gain greater understanding of the participants’ lived experiences (Holloway and Freshwater, 2007). The aim was to have a at least four people take part in the study, Marshall (1996) suggested,

An appropriate sample size for a qualitative study is one that adequately answers the research question. For simple questions or very detailed studies, this might be in single figures. (p. 523)

A recent qualitative study (Räisänen & Hunt, 2014), which was similar to this study, had 10 participants. Many of the qualitative studies involving men who experience EDs involved smaller numbers of participants; for example, Crisp and Toms (1972) (13 men), Hall et al. (1985) (nine men), Fernández-Aranda et al. (2004) (nine men) and Räisänen and Hunt (2014) (10 men). In an ideal world, the tenet of Marshall (1996) and Holloway and Freshwater (2007) of data saturation (the point where no new data or themes are being presented) being the ceiling for the number of respondents would be the goal. In light of numbers involved in previous studies, the issue of men who have an ED being reluctant to come forward, and after discussion with my supervisors, a realistic number of participants to interview was identified at being between 4 and 10 men, based on the sensitive nature of the research and the given time frame for PhD completion, with data saturation being unlikely.

With such a small potential sample size, many accepted methods to select a sample were not applicable. For example, it would have been impractical to use quota, stratified sampling methods or any probability sampling methods with such small numbers; therefore, it left little choice but to use a non-probability sampling method such as Theoretical Sampling. Theoretical Sampling is a qualitative approach, enabling the researcher to actively seek out those who can help answer the research questions. For this study, due to logistical considerations, this required me directly accessing available resources, such as Beat (the UK’s main eating disorder charity) and Men Get Eating
3.4.3.2 - Inclusion Criteria for Participants

The targeted group for this study were men over the age of 18, who have/had anorexia or because of classification difficulties of anorexia, an eating disorder non-otherwise specified (EDNOS)/a-typical anorexia. The study was also open to men who may have had no formal diagnosis from health services, but who accessed ED charities.

3.4.3.3 - Recruitment

Participants were not approached directly. As discussed previously the two main eating disorder charities in the UK were identified as go-betweens, and using theoretical sampling allowed this indirect approach, the groups acting as a hub for the target population. The methods used to recruit participants were:

1. Using the Beat volunteer database – Beat has a database of people who have stated their desire to help eating disorder researchers. At the time of recruitment, Beat stated, via an email conversation with their Research Officer, that they had 29 males on the database. The database was made up of males of all ages but did not solely consist of those diagnosed with anorexia, as people on it may have bulimia or be carers. Beat then sent private emails directly to people on the databases with the study’s information. In order to be able to use Beat’s resources certain criteria have to be meet, this is outlined in appendix 2.

2. Beat also has a section on its website (http://www.Beat.co.uk/support-us/get-involved/research/take-part/) where academic studies are listed for people to investigate and, if they wish, take part. When Beat were first contacted (April 2014) in relation to advertising this study they had some 40 academic studies being advertised on their site, with 23 being related in some way to anorexia (Appendix 3).
3. Both Men Get Eating Disorders Too and Beat have a social media presence and Facebook and Twitter were used to advertise the study, however it was unclear if MENGET actually ever did this and no men who responded to the study identified coming from MENGET’s posts.

4. The study was also advertised in the Salford Star, a local community news site. This attracted a lot of interest on social media from people in the eating disorders community, but sadly no one who went on to participate.

As part of the original ethical application to the University of Salford, the facilitators of eating disorder self-help groups were to be approached to help promote the study (via for example a poster in the meeting room or an announcement in a group session).

Unfortunately, as part of the criteria for getting help with Beat, this approach was unable to be used with any groups affiliated to the organisation. This was disappointing and, as means of trying to raise awareness of the study, abandoned. It was felt that it would be better to keep the promise of help and resources from Beat rather than ‘go it alone’.

The validity of using a national ED charity (Beat) as a tool in participant recruitment was called into question during University of Salford Ethical Approval process. This was puzzling as the number of academic studies who use/uses/used Beat indicates/ed that the academic ED community has/had no problem with this resource. Indeed, the National Institute for Clinical Excellence (NICE) used Beat to advertise a recent Guideline Consultation. Furthermore, Räisänen and Hunt (2014), a similar qualitative study to this, found their 10 male respondents by accessing patient organisations, health professionals and social media. The questioning by the University’s ethics panel illustrates the difficulty in being truly objective and reinforces the justification of the Interpretivist approach used. It also highlights how, no matter how objective the research, it is still at the whim of the audience’s interpretations.

The process of recruiting participants after the marketing of the study was kept as straightforward as possible,

1. The men responded to the advertisement (Appendix 4) via an official University of Salford email account (g.i.lyons1@edu.salford.ac.uk) and any initial questions were answered.
2. They were then sent an official Invite/response letter (Appendix 5) with a full advert (Appendix 4) and Participant Information Sheet (Appendix 6).

3. Each man was asked to look at the information attached and to confirm if they wished to continue to take part in the study or if they wanted further clarification.

4. When the men had confirmed they wanted to take part in the study they were then sent; a consent form (Appendix 7) and a demographic questionnaire (Appendix 8) to complete.

5. The men were again encouraged to ask any questions and informed that only on completion of the consent form would an interview be arranged.

6. When the consent form had been returned, an interview via a method of their choosing was arranged.

7. At the end of the interview the men were given a debriefing period, (they could ask any questions, let off steam and were asked if they needed help/how they felt). If they indicated they wanted further help/support they were given a list of healthcare contact numbers (Appendix 9). In total there were 14 responses, 13 men were sent paper work, with nine completing it and eight interviewed.

3.4.4 - ETHICAL ISSUES

Two codes of ethics guided this study; the first was the Declaration of Helsinki (World Medical Association, 2013) which deals with ethics concerning medical research involving humans. The second is the code of the Association of Internet Researchers (Ess, 2002) and Markham and Buchanan’s (2012) recommendations to the Association of Internet Researchers. However, to advertise the study with Beat, Beat’s Confidentially Policy (Appendix 10) had to be accepted and adhered to. This guaranteed anonymity in all but the most extreme circumstance, such as a threat or danger to the participant/someone else, or if a law is broken by not breaking confidentially.

There were a number of ethical considerations as with any study dealing with emotive issues, not least the distress that might be caused by the interviewee sharing their story. To address this, time was allocated at the end of each interview for the researcher to check how the participant was feeling in the immediate situation. This “cooling down period”
was not recorded and formed no part of the interview. Additionally, if needed, each participant was given a list of contacts (Appendix 9) regarding where they could access further support if required. Participants were adults and were made aware of the study’s contents before they took part and given a number of opportunities before, during and after to ask questions. They were also advised to discuss their participation in the study with a significant other, including health professionals. In addition to the above, there was a level of responsibility on the part of the participant to only consent to participate if they felt that they could do so without personal harm. This approach appeared to be successful, as, after initial approaches, four men decided, for whatever reason, not to participate in the study and one man decided on the advice of his health professional he was not well enough to take part.

In accordance with Beat’s Confidentially Policy (Appendix 10) and good practice, participants were informed through the Participant Information Sheet (Appendix 6) and at the beginning of the interview that in certain circumstances confidentiality may be broken and appropriate agencies informed. Such circumstances would include where there was a real and present risk to self or other, and when not to do so would be breaking the law on the part of the researcher. If this eventuality had occurred then this would only have taken place in full consultation with the researcher’s supervisory team or, if an immediate threat to life, a judgement call on the researcher’s part. Data was kept in accordance with the Data Protection Act (H.M. Government 1998). Participants’ contact details and responses were stored on a secure, non-network, password protected computer which had up-to-date firewall and anti-virus software. All printed information such as transcripts had all identifying names removed and were stored in a locked file.

With regard to support for the researcher, the primary supervisor has a background of being a registered mental health nurse and is familiar with giving clinical supervision to those working as counsellors and was happy to provide similar supervision should the need arise. In addition, the researcher’s personal supervisor was also willing to offer emotional support should it be required.
3.4.5 - DATA COLLECTION

Participants were asked to fill in a short demographic questionnaire (Appendix 8) in order to collect some background information. This allowed the narrative interviews used for the main aspect of the research, to explore what impact an EDs had on the lives of the participants, to flow better and make better use of time. The men were given the choice of using the interview method they preferred; most men chose a telephone interview, one man decided on a face to face interview and one man asked for an email interview.

3.4.5.1 - Narrative Interviews

Using a narrative method to collect data, the most practical way to gather information was from individual interviews. Narrative research is particularly useful when addressing difficult topics (Josselson and Lieblich, 1995; Bauer, 1996; Lakeman et al., 2013). In this study, the participants were asked about some of their most personal and inner feelings, the narrative method allowing the men to choose how they discussed these topics, with the onus on them in how much or how little they shared. The face to face and telephone interviews were recorded using a digital recorder. This enabled the creation of transcripts in order to aid analysis. For the sole email interview, the flow of written questions and answers formed a transcript.

3.4.5.1.1 - Structuring the Narrative Interview

I believe that all interviews have an element of narrative in them as there is a shared theme of storytelling, the difference being in the level of structure and thereby the interviewer’s involvement. The latter was one of my main concerns in trying to formulate an effective interview strategy.

A largely unstructured interview approach would have given the participants full rein to talk about what they wanted. One such method considered was Biographical Narrative Interviews (Wengraf, 2004). However, this style of a single question, interviewee monologue with chronological follow up clarification questions was discounted. With such a wide area being examined, i.e. the question asked would have had to have been similar to “describe how your ED experience has impacted on your life” there was a potential for a wide variety of stories which may have been completely unrelated. This approach was
adopted by O'Shaughnessy et al. (2013) whose narrative study on women’s experiences of anorexia followed Wengraf’s (2004) process of using a single narrative question. This was expanded with a follow up interview, based around themes which emerged from the first interview, and also periods of co-construction. However, only four women were interviewed using this method (O'Shaughnessy et al., 2013). Ross and Green, (2011) used a similar kind of biographical approach in their study of two women diagnosed with anorexia, using two semi structured interviews where the “women were encouraged to tell their stories rather than answer direct questions” (p113), and where co-construction in a third meeting was also used as a way of validating the interviews.

Although this approach looks to be an excellent way to explore a new topic, it is almost akin to a focus group in marketing. For this study, with an inexperienced researcher, it would have been a high-risk strategy to take. I personally had concerns over my own competence to be able to listen without asking questions for a prolonged period of time and not miss important information. Wengraf (2004) noted that such interview strategies need experience and training. I actually found that in the early interviews conducted in this study I was that afraid of missing something, keeping to the time limit, and not saying anything leading; and that in my desire to not do those things, I felt that in fact I did them all. However, the more interviews completed the more I felt confident in my ability to allow the participants to speak without me seeking clarification. I feel that using a more conservative low risk approach, that is on a one to one basis, was the best choice in the circumstances, especially as the majority of interviews in this study were conducted over the phone and were at the mercy of gremlins. For example, during one interview the participant’s phone cut out and another one of the interviews had to be redone as the participant’s voice was not picked up well enough for the interview to be transcribed. This may have impacted a one question biographical interview, due to having to interrupt the participants flow or redo the moment.

Whilst in some ways an unstructured as possible approach to interviewing (the interviewee has to be asked at least one question) can be viewed as ideal, I feel that without having clarification and elements of co-construction (during or after the interview) the researcher runs the risk of the hijacking the narrative with their own perceptions of events. I
personally experienced this within my medical history and it made me feel low, as the truth that I had told my therapist bared no resemblance to the paper version constructed.

Fraser’s (2004) work on narrative research proved a valuable tool in the creation of the interviews. Fraser (2004) suggested having a plan for conducting interviews (semi structured), but not being rigid and adapting to the flow of the data collection. Fraser (2004) also suggested being able to respond to the participant’s communication style, avoid cross examining, allowing participants to ask questions and to not hide the researcher’s investment within the research, would aid the process of collecting narrative data. Above all Fraser (2004) indicated the need for research to be interviewee focused and driven.

Given the above, the interviews took a semi structured approach. Each participant was asked a general question about their experiences on some of the themes highlighted within Chapter 2’s literature review. After encouraging them to speak freely about this and following up with some clarifying questions, when the topic was exhausted, the next theme was approached. I felt this offered up a balance between allowing the participants free rein and not missing something they may have said.

Asking questions to clarify or expand points allowed an element of co-construction. However, the participants were not approached after the interviews to examine the analysis written about their stories for formal and structured co-construction. Given my own experiences outlined previously, a charge of hypocrisy would be valid. However, it was a necessary evil to make the decision to not co-construct. A practical choice was made between less interviews that were co-constructed, or more interviews without co-construction. Co-constructed interviews would have involved going back to the participants, and whilst it could be argued it may increase accuracy, it would have meant, within a limited time frame, fewer interviews being conducted. Both Ross and Green (2011) and O'Shaughnessy et al.’s (2013) studies sought narrative experiences, but only presented four and two co-constructed stories respectively. Presenting a smaller number of stories would have defeated one of the unwritten goals of this study which was to try and present as many stories as possible, the more stories offering greater diversity of experiences. There was also an ethical concern with co-constructing, as by asking them to look in depth at their stories and offer changes/additions/amendments without an
opportunity of face to face discussion could have been a traumatising experience (McAndrew, 2008). Furthermore, there was also the potential of stories being watered down by the participants, although in the case of the men who took part in the study I do not think this would have been an issue.

3.4.5.2 - Email Interview (Asynchronous Interviewing)

The use of email as a tool in gathering primary information via an interview in this study was not the preferred method on the part of the researcher. However, this approach is thought to give respondents time for reflection and to write structured accounts of their experiences (Gibson, 2010). That said, there is also a question mark over the authenticity of the story being reiterated, as there is no direct contact with the participant, and therefore no visual or auditory references to help interpretation.

With the conversation being asynchronous, it can in theory, be a long-winded form of data collection unless there are clear boundaries in place as to the duration of the interview. Research has shown that dropout rates unsurprisingly increase the longer the interview takes (Meho, 2006). However, notwithstanding the limitations of the method, as no method is perfect, Meho (2006) suggested this can be a viable approach especially where there are financial constraints, time pressures and geographical boundaries to overcome. In this study, the participant who wanted to use this method was sent and asked to comment upon his feelings, experiences and opinions on a list of themes that were used as the skeleton guide for all the interviews. When the participant had done this, and sent his comments back, they were analysed using the same methods used for the other interviews and direct follow up questions appertaining to the participant’s original comments were sent in an attempt to make the interview as similar to the verbal interviews as possible.

3.4.5.3 - Demographic Questionnaire/Survey

A short questionnaire (Appendix 8) was given to the participants at the point of consent and before an interview was booked. It was split into two sections; the first asking for demographic information, the second section asking for information about the participant’s eating disorder. The demographic questions were, with the exception of one question, all open ended, concerned with collecting information about, age, sexuality, level of education, ethnicity and faith. The number of questions that had to be answered on the
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second part of the questionnaire were dependent upon whether or not the participant had sought medical help. If they had sought help there were eight questions to answer of which five were open-ended. If the participant had not sought medical help then they were required to answer six questions with four being open.

3.4.6 - DATA ANALYSIS AND REPORTING

Qualitative data is more susceptible to interpretation and valuation; with what is omitted from a report often being seen as more interesting than what is included (Walliman, 2006). As with all research, the data collected has had to have been sorted, sifted and then presented. In terms of this study the qualitative narrative approaches used whilst giving the men who took part a chance to share their experiences of living with an ED, was difficult to analysis as it depended upon the researcher’s frame of reference, speciality and experience. What one analyst may find interesting, another may not. The nature of this study in examining a broad range of experiences, rather than trying to pick specific details, makes the analysis in some ways easier and in others more difficult.

All information was collated using spreadsheet software (Excel), with only seven participants, completing both questionnaire and interview, and the simple nature of the questions, there was no need in using any statistical software (SPSS etc.).

Keeping the authenticity of the men’s stories was a concern during the analytic process. To achieve this the narrative interviews were firstly transcribed, they were then examined and the text coded using headings related to the themes which the interviews were based around and those which arose during the interviews, such as the influence of loved ones. For example, Richard’s interview (appendix 11), was coded with headings such as ED background, masculinity, ED portrayals and treatment. Each comment usually had a sentence added to it making clear why it was deemed important. Potential quotes were also highlighted in this way, as were questions to be raised with supervisors.

Each man’s story was then written using the coding of the interviews to create a narrative analysis. For each interview, comments and quotes pertaining to the same theme were placed under a main heading, allowing the story to be drawn together from the individual’s original narrative. This allowed a biographical account to be created which was a true reflection of the men’s words with a psychoanalytical interpretation to add meaning.
The second element of analysis was to compare and contrast the men’s stories and seek shared experiences. This then enabled a section of analysis to be presented where common themes from the men’s stories were extracted, examined and referenced back to the existing body of knowledge. However, choosing which themes to foreground was difficult, as some, such as the men’s treatment experiences, were easier to select than others, such as issues relating to employment; the latter perhaps appealing to a different range of people. All analysis was focused within the context of the research outline/title.

3.5 – CONCLUDING WITH METHODOLOGY

With the aim of this study being to explore the lived experiences of men with EDs and to create a platform for future research, an Interpretivist philosophical framework was appropriately chosen. Using people’s stories, experiences and emotions is a direct contrast to the spirit of traditional Positivist ideals of subjectivity. The information collated could not reliably be measured as both questions and answers are subject to interpretation. The study is also not repeatable in a positivist sense, as on a different day the question may receive a totally different answer as responses depend upon human feelings at a given point in time. Using Interpretivism allows for the gathering of experiences and, as such, using a narrative interviewing technique and analysis was deemed the most suitable to collect the information to fulfil the study’s aims.

In the following chapters (4-12) the findings of this study are presented. Chapter 4 offers a brief outline of some of the demographic/background data collected and the following chapters present each man’s story in the form of a narrative analysis. Chapter 12 draws together the main themes gathered from the interviews.
An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons
4.1 – FINDINGS OVERVIEW

In total 14 men responded to the various advertisements, and of these, 13 showed an interest in taking part in the study. The other response to the advertisement was criticism from a transgendered individual because the study was not focused on the transgender community. This individual was told they were welcome to take part so long as biologically they had been born male, to this they never responded.

The 13 men showing interest were sent information regarding the study. Of these nine completed the necessary paper work, including consent to take part in the study. Of these nine, eight were interviewed, six via the phone, one-person face to face and one respondent preferred to help via email. The ninth man removed himself from the study on health grounds before his interview and although he filled his demographic questionnaire in it has been excluded from the results. It was decided that one of the men (Martin), who had been interviewed despite being bulimic, would have his analysed data removed from the study and at a later date an attempt would be made to publish his story via an academic journal. This was done to avoid confusion to any reader of the study and also to ensure the research remained focused around anorexia and its variants, therefore seven narratives are presented. All of the men’s names are pseudonyms.

4.2 – QUESTIONNAIRE ANALYSIS

A short demographic questionnaire (Appendix 8) was sent to potential participants and they were asked to fill it in before the interview took place. Where possible the questions were left open ended, this was to give the participants opportunity to answer the questions in their own way. The questionnaire was used to gain some background data to potentially aid the interview process. For example, knowing a little information about each participant enabled me, as the researcher, to gain quicker rapport with each of the men and it also allowed me to be respectful and sensitive to the background of each man. Asking for demographic information also allowed me to consider those volunteering to participate in my study in comparison to a very similar study undertaken by Räisänen and Hunt’s (2014). A breakdown of some of this information is found in Table 4 on the following page.
Table 4 - Demographic Answers from Study Questionnaires

<table>
<thead>
<tr>
<th></th>
<th>Russell</th>
<th>Alan</th>
<th>Kevin</th>
<th>Henry</th>
<th>Stephen</th>
<th>Michael</th>
<th>Richard</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age:</strong></td>
<td>31</td>
<td>24</td>
<td>34</td>
<td>27</td>
<td>23</td>
<td>34</td>
<td>25</td>
<td>Ave = 28.29</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td>White</td>
<td>White</td>
<td>White</td>
<td>White</td>
<td>White</td>
<td>White</td>
<td>White</td>
<td>White</td>
</tr>
<tr>
<td><strong>Level of Education</strong></td>
<td>A Levels</td>
<td>A Levels</td>
<td>Post Grad.</td>
<td>Post Grad.</td>
<td>Graduate</td>
<td>Graduate</td>
<td>Post Grad.</td>
<td></td>
</tr>
<tr>
<td><strong>Medical Classification</strong></td>
<td>Anorexia</td>
<td>Anorexia</td>
<td>Anorexia</td>
<td>Anorexia</td>
<td>Anorexia</td>
<td>Anorexia</td>
<td>Anorexia</td>
<td></td>
</tr>
<tr>
<td><strong>Private/NHS</strong></td>
<td>Both</td>
<td>Both</td>
<td>Both</td>
<td>Both</td>
<td>Both</td>
<td>NHS</td>
<td>NHS</td>
<td>Both</td>
</tr>
<tr>
<td><strong>ED Manifestation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Food Restriction</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Vomiting</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Laxative Use</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
<td>Yes</td>
<td></td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Excessive Exercise</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Other (Diet Pills)</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Other (Amphetamines)</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Duration of Illness (yrs)</strong></td>
<td>4</td>
<td>7</td>
<td>19</td>
<td>11</td>
<td>9</td>
<td>19</td>
<td>8</td>
<td>Ave = 11</td>
</tr>
</tbody>
</table>

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons
4.2.1 - AGE OF RESPONDENTS

The average age of respondents was a little over 28 years, the youngest man being 23 and the oldest 34 years old. This puts the average age of the men in this study around eight years older than the men interviewed by Räisänen and Hunt (2014), whose study design was very similar, but whose average age was 20 years 4 months.

4.2.2 - ETHNICITY

All seven of the men identified as being white. This again is in keeping with Räisänen and Hunt’s (2014) study where 80% (8 men) of the sample were described as White British.

4.2.3 - RELIGIOUS BELIEFS

Only two of the men identified with any religious belief (Presbyterian and Zen Buddhist). Three identified being atheist, one answered none and one man answered the question with N/A which illustrated the open nature of the questionnaire allowing him to answer as he saw fit.

4.2.4 - SEXUALITY

Four of the seven men reported being heterosexual (57%), one man was bisexual (14%) and two were homosexual (29%). This differed from Räisänen and Hunt’s (2014) sample which was made up of a 70/30% split between heterosexual and homosexual men. This disparity could be the result of a number of reasons, for example, stigma within heterosexual men which prevents them coming forward to acknowledge anorexia or help with studies. By the same token, the wider acceptance within the gay community of anorexia would therefore reduce the stigma to come forward, help with studies and be more active in ED advocacy. There could also be a natural bias/coincidence within the sample.
4.2.5 - LEVEL OF EDUCATION

Two men were educated to A Level standard. However (stemming from the interviews) one of these men had to quit his degree course because of his illness and another had quit his career, partly due to his illness, and entered university as a mature student. Two men had degrees, and three men held postgraduate qualifications. From the sample of seven men, all of them of them had at some point been accepted and studied at university. There is no comparison with Räisänen and Hunt (2014) as the age range of their sample is much younger, having less life experience, and six of their sample being listed as students.

4.2.6 - EMPLOYMENT

At the time of interview all of the men were employed either full or part time. From the interviews one man was in the process of becoming a full-time student, one could only work part time and another was on unpaid leave from his employment. The men had a range of jobs in different sectors, all, though, could be classified as skilled workers. Of the four men in Räisänen and Hunt’s (2014) study who were not classified as being in education, two were employed and two were unemployed.

4.2.7 - SEEKING TREATMENT

All the men interviewed for this study had at one point or another sought treatment for their ED, all but one of the men had received medical help for their ED.

4.2.8 - ED CLASSIFICATION

All of the men identified being diagnosed with anorexia, with one adding the sub type binge/purge. However, during his interview Stephen stated that due to the classification criteria he was never formally diagnosed with anorexia due to his BMI and that “two of the needed criteria were only possible for women.” (Stephen Lines 246-47). This indicates some of the issues raised in Chapter 1 regarding classification and that Stephen himself identified his ED as anorexia.
4.2.9 - HEALTH SECTORS ACCESSED

Five of the seven men (71%) have accessed both NHS and private health care, with two men solely accessing the NHS. This could give rise to question the quality of care provision in the NHS, and perhaps might be a separate study with a more focused design looking at how, from a service user perspective, the NHS meets the needs of men with EDs.

4.2.10 - SERVICES AND TREATMENT ACCESSED (2 QUESTIONS)

A variety of different services had been accessed by the men including; inpatient and outpatient care, dietician/nutritionist, counselling, hypnotherapy, help lines and Accident and Emergency (A&E). In addition to different services being used, different methods of treatment were reported, including cognitive behaviour therapy (CBT), Schema Therapy, Psychodynamic Psychotherapy, Occupational Therapy and medication. To some degree the open-ended nature of the questions was unhelpful in gaining clear answers. For example, only one man reported medication as a treatment, yet during the interviews others also mentioned it. A list of the main services and treatments would perhaps have been a better way to ask these questions.

4.2.11 - EATING DISORDERED BEHAVIOUR EXPERIENCED

The questionnaire asked men to clarify if they had engaged in any of the following behaviours: Food Restriction, Vomiting, Laxative Use, Excessive Exercise, Other. All seven men reported food restriction, with six of the men (85%) also reporting excessive exercise. This high percentage of men engaging in excessive exercise is in keeping with evidence within the literature, showing it to be a common and popular way in which males with eating disorders lose weight (Dissing et al., 2011; Murray et al., 2012; Strother et al., 2012; Younis and Ali, 2012; Murray et al., 2014). Vomiting and laxative use was reported by four of the men. Additionally, one man reported using illegal diet pills and amphetamines to control his weight. However, as each man could answer an affirmative to all of the behaviours and list additional ones, a full break down of how the various combinations that were identified were used is displayed in table 5 below.
An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or atypical anorexia/EDNOS

<table>
<thead>
<tr>
<th>Combination</th>
<th>Number</th>
<th>Sexuality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food Restriction</td>
<td>1</td>
<td>Heterosexual</td>
</tr>
<tr>
<td>Food Restriction, Excessive Exercise</td>
<td>2</td>
<td>Heterosexual</td>
</tr>
<tr>
<td>Food Restriction, Excessive Exercise, Vomiting</td>
<td>1</td>
<td>Bisexual</td>
</tr>
<tr>
<td>Food Restriction, Excessive Exercise, Laxative use</td>
<td>1</td>
<td>Heterosexual</td>
</tr>
<tr>
<td>Food Restriction, Excessive Exercise, Vomiting and Laxative use</td>
<td>1</td>
<td>Homosexual</td>
</tr>
<tr>
<td>Food Restriction, Excessive Exercise, Vomiting, Laxative Use, Illegal</td>
<td>1</td>
<td>Homosexual</td>
</tr>
</tbody>
</table>

In total, vomiting was identified as a method of purging by 43% of the men, as were laxatives. It must be stated that two men used both vomiting and laxatives as a method of purging. This contradicts the findings of Núñez-Navarro et al. (2012) who found that men tended to prefer to use vomiting rather than laxatives as a method of purging. However, the question indicated gay men used more (and more extreme) methods to control their weight. The two gay men in the sample both restricted food, exercised, vomited and used laxatives.

4.2.12 - DURATION OF EATING DISORDER

The average duration of eating disorder behaviour, as reported by the sample, was 11 years, with the shortest episode being four years and the longest, in two cases, 19 years. By subtracting the age of the interviewee and their believed duration of their eating disorder, an approximate age of onset of their eating disordered behaviour can be identified. The average age for the first episode of an ED was 17½ years, although this average is skewed as one respondent was 27 at the age of his first incident. However, the median and mode is 15 years respectively at the time of the first episode. (See figure 5 on the following page)
As discussed in the literature review of this thesis, academic research is extremely confused as to the age of onset of EDs in males, with some academics, (Crisp et al., 2006; Gueguen et al., 2012) finding the age of onset to be around 20 years, whereas Fassino et al. (2001) and Lindblad et al. (2006) identified a much earlier age of onset. The age of onset in this study leans towards the findings of Fassino et al. (2001) who suggested the age of onset being 16.5 years. However, these were self-reported ages by the interviewees and may not be conclusive or reliable. Similarly, the age of onset may differ in research findings depending on the definition of ‘onset’. In some studies it may be classed as when the person with the ED first exhibits associated behaviours or it could be when they are first diagnosed. The above demographic data provides an overview of some of the characteristic of the men participating in this study, and how they compare to those in other published studies.

The rest of this chapter will now be dedicated to the analysed stories of the seven men who participated in this study. The narratives are presented with some analysis interspersed within each interview rather than solely at the end, as in, for example, Browning (2017). This was to do to show my thinking as it progressed through the analytic process. In addition, it also shows analysis of some points which were not carried through into the final drawing together of emergent themes (Chapter 12).
CHAPTER 5 - HENRY’S STORY

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons
5.1 – OVERVIEW

Henry was a white male in his mid/late 20s. He was by his own description “small and quite feeble” (Henry line 305). At the point of interview, he had experienced around 11/12 years of eating disordered behaviour, starting around the age of 15/16 and focused around food restriction, laxative use and excessive exercise. As part of the interview debrief, Henry was told that if he wanted to add anything to his story he was more than welcome to send a separate email with his thoughts, which he did.

5.2 – BACKGROUND

5.2.1 - FAMILY

In his own words, Henry’s relationship with his family was ‘good’. He grew up with both his mother and father. Henry wrote in a separate email (Henry’s email, 15th Jan 15) that “there is depression in this family” (Henry Line 16) and in a follow up email (Henry’s email, 10th April 15) he clarified that his mother has experienced depression. His father was diagnosed with sleep apnoea and was given medical advice to lose weight, given the seriousness of the condition. Both his father and mother went on crash diets at this point, which coincidently was around the same time that Henry began his own eating disordered behaviour. Whilst one interpretation might be that the impact of both his parents being on diets may have influenced his own eating behaviour. Another explanation may be the seriousness of his parents’ illnesses, each having the potential to be life threatening, and the insecurity, and perhaps consequential anxiety, this may have caused him.

Henry has two siblings, a brother (who is three years younger) and a sister (who is seven years younger). Henry’s brother has a diagnosis of Obsessive Compulsive Disorder (OCD), which Henry believed had not impacted upon him. Henry’s sister was “very overweight as a teenager” (Henry’s Email 10th April 15 line 36) which was due to undiagnosed celiac disease (identified when she was 19). The weight issues of Henry’s sister cannot be used as a factor in his illness as Henry’s eating disorder manifested when his sister was around 7-9 years of age. However, interestingly, celiac disease has been associated with eating disorders. In a longitudinal study, Leffler et al. (2007) found that...
2.3% of female patients they treated either had celiac disease and an eating disorder, or they had celiac disease that was in fact identified as an eating disorder.

### 5.2.2 - BACKGROUND MEDICAL CONDITIONS

Around the time Henry sought treatment for his eating disorder he was diagnosed with Hypergonadotropic Hypogonadism; in layman’s terms this is a deficiency of testosterone which in Henry’s case reduced/slowed puberty. This in itself is interesting, as testosterone deficiency is a common effect of starvation syndrome (identified by Keys (1950) see chapter 1.4.5), which is often apparent in anorexia. Simplistically, when the body does not have enough energy to sustain itself over a period of time it starts to shut down non-essential systems, with reproduction being one of those affected first; this in turn affects hormone production including testosterone. What is especially interesting in Henry’s narrative is the question raised by the diagnosis of Hypergonadotropic Hypogonadism and if this was a result of his anorexia or vice versa. In Henry’s narrative there is some confusion when he spoke of the background to his illness, talking of his anorexia and testosterone deficiency as almost separate. His reporting of having testosterone injections to boost his hormone levels does not seem to initially be part of a holistic approach to anorexia. As time has progressed, and at the point of interview, Henry reported,

> I’ve been told now that it was initially idiopathic. They don’t know why my body can’t produce it. But they’ve reassessed, they said, ‘okay! We reckon that your body doesn’t produce testosterone because it’s technically in body shock, you might be able to produce your own testosterone if you’re at a more optimal weight’ (Henry lines 356-360).

The above statement would indicate that, initially, Henry’s clinicians did not realise or link the importance of his low body weight in the production of testosterone. Such a conclusion seems harsh, but in the light of Henry’s narrative and what he has said, it is logical.

Henry felt he had OCD and self-diagnosed himself from his brother’s experiences. Although self-diagnosis is open to criticism, it is interesting that men with anorexia have been found to have high numbers of obsessive compulsive traits (Raevuori et al., 2008). Perhaps this is not surprising, given that both types of illness are characterised by the need to be in control and there is much debate on the links between eating disorders and OCD with co-morbidity often occurring (Altman and Shankman, 2009).
5.2.3 - EDUCATION

Henry had both undergraduate and post-graduate degrees, both with high grades, and this is in keeping with the general consensus that despite the trials of anorexia, people are able to continue to focus on their education and achieve high grades. Likewise, there is evidence to suggest that those who experience EDs aim to be high achievers and again it is seen as a way of achieving perfection (Andersen and Mickalide, 1983; Treasure, 2005), perhaps in both body and mind. University for Henry was the breaking point, as it is at this point he sought help. However, although Henry achieved his educational goals it did come at a price. Henry found himself extremely isolated, and it appears he did not take part in any university life outside of the lecture hall.

The strain of anorexia saw Henry in his own words have a “nervous breakdown” (Henry line 39) at around Easter time in his first year of university. At this point he made the health services aware of his predicament and engaged in treatment. Throughout his time at university (approx. 4 years), Henry only missed handing in one assignment, an assignment which he reported was an optional one and had no bearing on his degree classification. Henry had to have an extension because of his health on his post-graduate dissertation in order to complete, perhaps indicating his ED had become worse.

5.3 – EATING DISORDER

5.3.1 - MANIFESTATION OF THE EATING DISORDER

In hindsight Henry first thought that he experienced ED behaviour around the age of 15/16, however it was not until his first year at university that he actually sought treatment, when he felt at a low ebb physically and mentally. Henry was diagnosed with anorexia and, in his demographic questionnaire and interview, acknowledged he excessively exercised and used laxatives, although in his interview he made no mention of his use of laxatives. Henry stated that his eating disordered behaviour changed over time. Initially he started by “just gradually cutting things out of my diet” (Henry lines 27-28) and then “my diet became so restrictive and then taking on very obsessive-compulsive exercise regimes” (Henry lines 30-31) to the extent that he was exercising before and after meals. At university, Henry stated that he would exercise for 3-4 hours daily. Such ritualistic
behaviour would see him become isolated, and even if he wanted to engage socially with people, his time was taken up satisfying the needs of his eating disorder. This pattern of behaviour (restriction and exercise) ebbed and flowed in the following years.

5.3.2 - EATING DISORDER GOAL

In hindsight, with his father being advised to diet because of his sleep apnoea, the isolation Henry felt and his own physical stature, it may not be surprising that Henry began to get “into more exercise and not eating or cutting out things, red meat, high fat foods and that kind of stuff.” (Henry lines 97-99). Equally, at a wider societal level, and given Henry’s small physical size, role models such as Jackie Chan and Bruce Lee, both themselves small men, may have influenced Henry’s desire to do something positive with his health, as they both projected physical power much greater than their size, yet they both could be viewed as being counter culture figures. Over time Henry felt challenged to do more about being able to control his body shape, such desires being in keeping with many men who experience anorexia, that is to become more muscular/athletic (Cooperman, 2000; Núñez-Navarro et al., 2012).

5.4 – HOW PEOPLE REACT(ED) TO HIS EATING DISORDER

It was interesting to hear how Henry perceived how people reacted to his ED at the time of his diagnosis and how people react to it now. This was covered in a section of the interview and resulting transcript that may be a little shorter than expected, when considering the importance and time span of the ED in his life. It is perhaps what was not said, and by whom, that was most revealing as to Henry’s experience of living with anorexia. Henry stated that he did not really know how people reacted to him, saying;

I think I was completely living in my own bubble world of private hell really, you know, not very aware of things going on around me in terms of actual personal stuff, human stuff around me, completely alienated. (Henry lines 205-207)

The above is suggestive of disassociation. He talked of “personal stuff”, “human stuff”, being very different from him being in his “own bubble world of private hell”, “completely alienated”, as though his illness separated him from his humanness. Perhaps, being so
wrapped up in themselves trying to understand what is happening, is one of the reasons why people with EDs are often associated with selfishness (Roehrig and McLean, 2010).

5.4.1 - FAMILY

When asked how his family had reacted to his eating disorder, Henry responded by saying it had been “hellish for them” (Henry Line 197) particularly his mother, who became very upset. He later stated that; “she’s a very sensitive soul and in dealing with my eating disorders has a tendency to be melodramatic and lurch into despair” (Henry’s email 10th April 2015 lines 18-19). Henry felt that when his family get/got upset with his condition and the behaviour associated with it, it helped him to gain some understanding, clarity and extra motivation to control himself. This was extremely interesting considering how Henry reported his behaviour when away from his loved ones at university (Section 5.2.3).

5.4.2 - FRIENDS

At the time of his original diagnosis, Henry was at university and stated the “people around at university just, I guess, were not aware” (Henry Line 203) of his anorexia. This would be in keeping with Henry describing himself as a “sociable loner” (Henry Line 178) and stating of life at university as;

I was just isolating myself. I wasn’t able to eat and was just forcing through exercise regimes that were taking up to three or four hours per day, feeling stressed out with university work and unable to kind of function. (Henry Lines 125-128)

His routine at university seems to have consisted of attending his lectures and doing his work, whilst using his free time to exercise. As he progressed into his 20s Henry stated that he had experienced some very good friendships but did not have many close friends and struggled to have a social life. His ED is something that he did not generally discuss with people, stating that it is something personal to him. He could only recollect telling one person in the previous twelve months before the interview, and that was because this person had similar issues with weight and there appeared to be a level of empathy.
5.4.3 - EMPLOYMENT

Henry had been unable to hold down a full-time job due to his health and currently worked in short term roles. When asked about how potential employers viewed anorexia induced gaps in employment he stated “I tried to cover over those periods saying I was in hospital for a time or I was ill, I think that’s as vague as I left it.” (Henry Lines 865-866). Surprisingly, given the previous sentence, Henry told his employer (at the time of interview) and assured them that he will not cause any problems.

5.4.4 - HENRY’S REACTION

Henry’s reaction and opinion of his anorexia at the time of the interview was illustrated in his reasoning for not speaking to people about it. Henry said,

I think it’s more my perception that it’s negative that it becomes something that makes me quite insecure in myself. I guess, like, I want people to think good of me, I want people to like me! I feel that my idea is that it’s just an all-consuming black hole (laughs), it’s just like putting a stain on you. I guess I have avoided more actually talking about it, I feel like I just become an irritant. (Henry Lines 665-670)

Henry identified being ill as negative, a “stain” on him, and talking about it makes him become an “irritant” to others. Within these statements, Henry appeared to believe that “others” go through life without ever being ill. Perhaps for Henry it is the shame he attaches to his illness that is the underlying problem. In his email reflections (Henry’s email 15th Jan 15) on the night of the interview, he wrote that he realised the key word that he had not used during the interview was “shame”.

I realised that the key word eluding me was ‘Shame’. My own experience with anorexia - one of the reasons I’m reluctant to speak about it in public, personally face it, etc. - comes down to shame. It’s a critical word for me with regard to my illness, and I’m surprised that it didn’t somehow end up being said today! (Henry email 15th Jan 2015 Lines 9-13)

Following on from Henry’s comment during the interview, regarding his unwillingness to speak about his ED and his belief that it irritated people, I asked Henry “why are you here, then? What are you doing here today?” (Henry Lines 677-678). He responded by saying “I guess I came here today mostly because it’s that anger. For me personally I see this as a
An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons

way I can deal with this. Face this!” (Henry Lines684-685) This indicated that he saw telling his story as a way of therapy (Warne and McAndrew, 2010; Lakeman et al., 2013).

Before Henry was ill he was isolated and he said that, post ED, he is “definitely more isolated” (Henry Line 184). When Henry stated that he was angry I believe that one of the major factors for this is his increased isolation. This is based on the comments he made immediately after mentioning his anger when he said, “I know that you’re doing research into male eating disorders and as I said I don’t see anything… that might be because I’m not looking in the right places or just not looking at all.” (Henry Lines 688-690). This indicated that he felt he had to do something, as not enough was being done to help men at the time. Furthermore, Henry finished by stating that he may not have been looking in the right places or at all. If he was looking and was unable to find the information that he needed, the isolation he felt may well increase. If he was not looking, then why did he respond to an advert to take part in a study?

It’s an effort because if, in the long-term, eventually, maybe years and years down the line, people have more of a handle of ‘yes, eating disorders do actually exist’. And they happen to other people beyond the actual stereotypical very basic idea. Then I am completely open to sharing that, especially in this kind of environment (Henry Lines 694-697).

I believe that his isolation is shown by the preceding quote. When Henry talked about the stereotypical idea of anorexia, he was referring to a view of anorexia being a young female illness, which Henry often mentioned (Henry Lines 282-283, 291-292, 569-570, 574-574 and 591-592) as something that made him angry, especially with his experiences of different demographics during his inpatient treatment. The final comments he made immediately after stating his anger, and which I believe can be attributed to isolation is “when I was in day care treatment I did do some blogging and I engaged with online communities a bit to do with mental health just in general” (Henry Lines 698-99).

However, this appeared to turn sour “I felt the communities were quite toxic, it felt dangerous” (Henry Lines703-04), he continued “I think that you can spend time with people, people with mental illnesses and it can become quite... I’m trying to think of the right words, draining and distracting to your own health” (Henry Lines 705-707). Henry’s attempt to engage with online communities did not work for him, although my questioning was remiss as I should have asked what type of communities he engaged with, my
assumption and feeling is that it was with communities trying to beat illness, rather than “Pro-Ana” sites. However, no matter what the community or the validity of Henry’s reasons for disengaging, when a person feels they have to turn away from potential help, it can perhaps have the effect of being another door closed in their face and another reason to isolate oneself.

When asked if he had encountered any negative reactions from the people he has told Henry replied, “I don’t know if I can say I’ve had negative reactions.” (Henry Line 665), which is perhaps a further reason for his anger to come from his own felt isolation and shame. His own reaction and ownership of his ED is extremely revealing. When speaking about why he often does not reveal his history he said;

I do see it as something quite personal and I think generally I view it as something in the past, even though it’s not in the past! It’s something I’m trying to move on from, and I try and not make it relevant and affect me. So, it’s like something I don’t want to identify with and that has been problematic in times when I’ve been trying to have treatment, because if you’re not identifying that there is a problem then you’re avoiding things (Henry Lines 636-41).

By keeping his thoughts, feelings and experiences within, Henry himself recognised this as a barrier to his own treatment. In some ways, by trying not to become an irritant or burden on people, he will have prolonged his illness. Perhaps he has made it worse and made himself more of a burden.

5.5 – SEEKING TREATMENT

Henry sought treatment in his first year at university. Although he knew something was wrong, he was unable to articulate what it was. Given his age and his intellect this appears surprising, but perhaps his in-articulation of the illness was an unconscious form of denial that protected his psychological well-being. Defence mechanisms are unconscious strategies that protect human beings from stressful situations when they are unable to accept what is happening to them (Bateman & Holmes, 1995). Henry said; “I didn’t know what was wrong with me, there was no kind of.... I was just in a state. I don’t think I consciously, like, went because I was worried about eating disorders.” (Henry Line 104-107)
What was interesting from Henry’s statement was that he was oblivious as to what could have been wrong with him. At the point of seeking treatment, he had engaged, for around two and a half years, in various levels of restrictive eating and excessive exercise, perhaps at this point also abusing laxatives. Yet an eating disorder had not crossed his mind. This may seem hard to believe to the lay person, however, ignorance within men to the symptoms of EDs and their ability to get them has been identified as a barrier to treatment (Cooperman, 2000; Paterson, 2004; Soban, 2006).

When asked what he thought was wrong with him at the time, Henry replied; “I don’t know, just self-loathing, self-hatred, it was self-destruction is what it was... Just inability to be like other people. It was just depression.” (Henry Lines 119-121)

5.5.1 - TREATMENT

From first contact with his GP at the age of 18/19, Henry has been involved at various stages with NHS treatment, having experience of inpatient and outpatient treatment, therapists and counsellors, as well as dieticians. When asked to describe his thoughts on his experiences of treatment, Henry replied, “endlessly frustrating...... not pleasant!” (Henry Line 248). First diagnosed whilst away from home at university, Henry has experienced treatment in at least two different NHS trusts and four different treatment centres. (My inability to be concrete regarding this relates to his narrative of the treatment he has received being a little confusing.) However, Henry’s experience of treatment is exemplified by his comments that to be successful you have to “buy into treatment” (Henry Line 284) and he felt that he was trying to buy into something that “didn’t quite relate”. (Henry Line 298)

5.5.2 - OUTPATIENT/DAY CARE

Day care proved problematic for Henry. Firstly, because he was only ever in treatment with females whom he did not relate to, and secondly because he thought that the stereotypical views of EDs were “probably reinforced a little by members of staff” (Henry Lines 284-285). This is an interesting viewpoint and is a recurring theme in his narrative about his treatment. Henry viewed his ED as a personal issue and that everyone needs different care, and rejected the gender leaning he felt he experienced towards female
patients within services. He highlighted having to fill forms in about body shape that in his view were female specific. For example, worksheet question and answers such as, ‘I think my bum looks right, I think my stomach looks right’. He felt that he could not relate to this treatment.

Henry highlighted that during his day care, he had to take public transport from his home to the hospital unit, was approximately a 60 to 90-minute journey each way. When he was at the day care centre he had to, in his own words “squeeze three meals within the space of three hours.” (Henry Line 737). This does not reflect patient centred care and it is understandable why he felt so negative towards his treatment; his lack of improvement in day care resulted in him being referred to inpatient treatment.

**5.5.3 - INPATIENT TREATMENT**

If Henry felt that inpatient treatment was going to be the answer, he must have soon changed his opinion as he referred to his 6-month’s hospitalisation as “like a prison” (Henry Line 254). When talking about inpatient care, using terminology such as “loss of liberty” (Henry Line 254) and “go on leave” (Henry Line 633) reinforced his dislike of his treatment. Perhaps the most compelling and defining comment about his opinion of inpatient treatment was “I think it would take something pretty epic to trump that [inpatient treatment] as the worst experience of my life, ever!” (Henry Lines 249-250). To describe treatment, which is supposedly designed to make you feel better, in such a dramatic way led me to question why Henry felt this way.

Henry stated that he felt treatment was “condescending and patronising” (Henry Line 266), especially in inpatient care where his isolation was even more marked, as he was unable to relate to the other patients. For a short period of time there was another male on the ward, but Henry found it difficult to relate to him and the female patients. Henry said “I think it was just such a horrible experience being with other eating disorder sufferers on the ward.” (Henry Line 264-66). This statement could be construed in a number of ways; perhaps it shows that Henry wished to isolate himself; it may be that as a more private person, particularly regarding his illness; or he struggles to show empathy; or the distress of others caused him pain. Henry said that one of his treats in life is to “visit the cinema every week” (Henry Line 633), but having inpatient care meant that he could not do this and I
feel that perhaps this, his loss of liberty, contributed to him feeling entrapped. Perhaps another reason for his feelings of being trapped could relate to the location of the hospital inpatient unit. The unit was approximately 50 miles and a one-hour drive away from his home and family, which was not helpful for his family to travel each way and for him to not have them close. Although it must be stated that many people and families have greater distances to travel to specialist units. On a more positive note Henry stated that he did engage in psychological therapy from a particular clinician whilst in inpatient care which he felt was really helpful, but he was discharged during this and never received any follow up appointments. Whatever Henry’s reasons or justifications, his story is not a good advertisement for inpatient care, with him stating “I can’t remember the name of the place. I’ve scrubbed it for my memory” (Henry Line 225).

5.5.4 - DIETICIANS

Henry’s opinion of the role of dieticians in his treatment was given before I had asked the question fully, his one-word answer being “useless” (Henry Line 532). When asked to elaborate on this, he talked of knowing that he had a problem with restriction and was trying to beat it. Like many people with an eating disorder Henry had a very good awareness of what a healthy diet should be and the nutritional values of food. For Henry, a person giving him diet plans and information is in some way superfluous to his requirements, and to a person who is in denial of their ED it could potentially be seen as a hostile intervention. Indeed, Henry felt that the diet plans he was put on only worked in the confines of hospital. Henry suggested;

It’s only practical when you’re stuck on an inpatient ward and you can follow through. Once you get out the world doesn’t run to the specific times of a hospital schedule and you can’t enforce everything (Henry Lines 549-551).

The above is valid, as it is fair to say that in the hospital environment the responsibility for eating, portion sizes and meal times is in many ways taken away from the patient. Perhaps in Henry’s case, his experience of having to have three meals in a short space of time while receiving day care may have created further barriers regarding his diet when he was admitted to hospital, as he was already resistant to health professionals trying to influence his consumption, and was well aware of what and how much he needed to eat.
5.6 – WEIGHT, BODY IMAGE AND BMI

Henry was asked how he felt about being free of an ED, his response being that there was a fear of the unknown, of normality, but he did not think it would happen as he “can’t honestly get my head around the notion of weight” (Henry Lines 776-77).

Weight is something, I feel quite detached from my body. I know I live in it and I know that I feel very tired and heavy in it. Even though I know I’m not heavy. I can’t judge it, I only have a few moments where I’m walking out and about and I’m exhausted or I realise when I occasionally see myself in the mirror, I see myself next other people and it’s ‘oh I’m quite a slight person’ ... ‘I’m a small slight person.’ I don’t know whether it’s body dysmorphic, but I don’t know how to judge my own body, I can’t honestly, objectively get a sense of size or weight or anything like that (Henry Lines 778-785).

From the preceding quotation Henry’s long-term prognosis looked bleak, he has had in and outpatient treatment and still has no real concept of his body nor the ability to be comfortable in it. It appears from Henry’s transcript that there was very little discussion about his body image, shape and what a healthy male may look like. Henry stated; “we had some group discussion sessions on it in day-care treatment but there wasn’t a moment you think you look like this but actually you look like this. No there was nothing on those lines.” (Henry Lines 790-92)

Henry went on to talk about the role of BMI, and while he acknowledged it was useful as a guide for health, he was also quick to point out that it does not take into account the actual body type.

I know that there are so many athletes who’ve got particular BMI’s and it’s like you’re obese, and it’s like no you’re not, you’re an American footballer, you’ve got all this muscle mass. My gripe with BMI is it’s being used as a yardstick for health (Henry Lines 799-802).

Henry appeared to have strong views about the use of BMI, and there being a need for it to be used more responsibly.

My particular issue to come back to treatment on the way things go. I know that it was one of judgements of whether you should be submitted to inpatient care or how much care you should receive depending on how low your BMI is. There is an incentive for people to make themselves even sicker to get the help they need! (Henry Lines 803-07)
The image that people have to make themselves even more ill in order to access treatment is graphic, descriptive and alarming. In his own experience, BMI was used as a gauge of his healthiness and well-being, and whether or not he could be allowed to fly to work in summer camps abroad. Henry was asked “are you willing to be 16 BMI to fly?” (Henry Lines 809-10), an approach which was in his words; “very arbitrary. I don’t think it’s necessarily healthy” (Henry Line 812), but the implication is that once you get past a BMI of 16 you can be considered physically well. However, what a BMI is unable to do is gauge mental wellbeing, and treatment predicated on this leaves a lot to be desired.

### 5.7 – INFLUENCE OF LOVED ONES

In Henry’s case, and by his own observations, the absence of loved ones had been a consistent factor in a number of incidents in his life, where his eating disordered behaviour escalated. Within his transcript there are four examples of this.

Firstly, whilst Henry’s eating disordered behaviour started when he was still living at home with his parents, his involvement with the health services did not start until he was in his first year at university living in the halls of residence and he could no longer function. Henry himself identified this as an important point in his life. “I think that was a crucial point where I could either go forward and recover some strength as it were or just go downhill and I went rapidly downhill at that point.” (Henry Lines 99-101). One conclusion may be that, although Henry experienced lots of family problems, mostly related to illness, not being within the family unit left him alone and unsupported to deal with his illness. Henry’s illness could have been a way of fitting in with the family pattern of illness, but in the hierarchy of illness him not being able to establish a place for himself and/or not wanting to further burden his parents. The power of family cannot be underestimated, and the dynamics of Henry’s family environment could be construed as unsupportive.

Henry also highlighted an incident when he house sat for someone during a winter, he said; “I kind of looked at it as an opportunity to get away. I was in a very low place at that point and I shut myself up in this person’s house with these two cats and basically didn’t eat and exercised a lot and made myself very very ill.” (Henry Lines 55-58) This perhaps shows a paradox often seen in health care, where the person who is ill wants isolation, but...
this results in further behaviour that compromises wellbeing. Again, in this incident Henry is isolated from his family.

Thirdly, and as reported previously, Henry’s experiences of treatment have been negative, especially his six months in an inpatient unit. I alluded to the distance and journey time that his family had to make to see him (5.5.3) and reiterate that perhaps this increased isolation from his loved ones, especially in an environment in which he felt trapped, would not have been totally conducive to his recovery.

Lastly, as part of his current employment, Henry has short term contracts in European summer camps. He stated,

  I’m a highly motivated person. I lose weight easily when I’m very active. The continuing narrative is it depletes me physically and mentally. I have to spend recovery time doing that (Henry Line 837-841).

  I did one summer and by the end of it I was very, very ill. I ended up catching a cold and physically I know my immune system is crap (laughs) because of eating disorders (Henry Lines 873-875).

Both of these quotes indicated that, away from his family, he could not control his calorific intake and expenditure.

Henry stated that he feels he is past this and he understands how to manage his condition better. However, he also went on to say; “I know that at times where I’ve been away on my own and been left to care for myself, I’ve reacted badly.” (Henry Lines 52-53). I think that this latter statement is further evidence of the benefit of having loved ones around and/or being part of friendship groups.

In his follow up email (Henry’s email 15th Jan 2015) Henry wrote,

  I wouldn’t blame my own behaviours around food on my family (though I can see compulsive personalities, perfectionist tendencies, anxiety and control freakery around me!) The environment at home is not ideal, but I ended up with anorexia because of my own mind and not because of the relatives around me who have consistently been supportive even when they have been completely confused and at a loss as to how to handle things. I’m fortunate in that regard (Henry’s email 15th Jan 2015 Lines 18-23).

This quote can be interpreted in many ways. It has been suggested people with anorexia will blame themselves for their experiences and put the thoughts and feelings of others
before their own (Treasure, 2005). What is interesting about Henry’s comment was that he felt the need to defend his loved ones, when no one had attached or insinuated blame.

5.8 – MASCULINITY

Henry’s views of masculinity were interesting and maybe show some confusion within him. Henry said he had; “never kind of been bothered about masculinity as much. I’ve seen myself as very androgynous as it were.” (Henry Lines 477-478). Henry described himself as physically being small and feeble, seeing himself as being androgynous. The addition of his being androgynous is strange, and in a society that talks in terms of masculinity and femininity is problematic. Henry stated that he was unsure how much stock he placed in gender roles, yet in his next sentence he stated that he would like to be “quite masculine” (Henry Lines 484).

In terms of male role models, Henry said;

From my background ... I’ve been around a lot of, I guess, traditional male people and that kind of stuff. So, I recognise that and I recognised that I kind of resisted a fair few of these people as well, and so I’ve not identified with it. I haven’t aspired to necessarily embody some of those traits that would be considered traditionally masculine. I don’t know if that kind of, like, pushed me more towards eating disorder behaviour. I think when I was looking around... I guess a few yobbish people around me at school and I felt alienated from them, maybe there is something in this? (Henry Lines 495-503)

The words at the end of this statement from Henry are interesting from the point of view that he is talking as though he is formulating his own thoughts. His comment “maybe there is something in this?” (Henry Line 503) is almost as if it is the first time in the trajectory of his ED he has been asked about masculinity. What is quite clear is that he consciously or unconsciously rejected the models of masculinity that have been around him growing up.

5.9 – EFFECTS OF ANOREXIA

5.9.1 - LIBIDO

Henry stated that his libido has been affected throughout his illness, and reported never having had any intimate relationships; he did state that he felt he was heterosexual. He has at times been unsure whether his low or absent libido was due his anorexia or...
Hypergonadotropic Hypogonadism and delayed puberty. This area is one of confusion for Henry and perhaps further complicated by stereotypical ideas regarding gender. Henry explained; “I know that I haven’t had any sex drive, any libido. I feel... I know when I think I’m doing a bit better because I feel I got more lust for life. I’ve got more interest in members of the opposite sex.” (Henry Lines 367-369)

5.9.2 - SEXUAL ABUSE/HARASSMENT

A relationship between sexual harassment and eating disordered behaviour has been found in previous studies, with men more likely to adopt compensatory behaviours (Buchanan et al., 2013). Henry did not believe that he has ever been harassed or abused, although he did easily recall an incident in response to speaking about this aspect of his life;

I remember when I was like 13, a young teenager about 13, girl in my class who was obviously very knowledgeable in these things started to try, you know, for a joke, to feel me up, I rejected that. That upset me but that’s not, I don’t consider that [harassment] (Henry Lines 447-450).

This was a strange response. Whilst it may have no bearing on his ED, it should not be discounted completely due to 1) the speed of Henry’s response, 2) him actually sharing this information and 3) his continuing narrative where he told me; “I used to have a GP who is particularly sleazy and I had to see him last year to get some medication... He was very unpleasant.” (Henry Lines 454-455)

5.10 – EDS IN THE WIDER COMMUNITY

5.10.1 - OPINIONS OF ED PORTRAYALS

Henry’s response when asked about male ED portrayals stated; “If they’re portrayed at all! I just don’t see it, I really really don’t” (Henry Line 563). He did comment though that, when on the occasions that he did see something about EDs, it was often around young males in sport. He was particularly scathing on how he felt EDs are often simplified into a good news story of anguish with a happy ending, giving the impression that the ED is almost a tap which can be turned on and off. He said of this “the narrative is magically ‘and then I got better’” (Henry Line 587-88). Henry highlighted the former racing driver David Coulthard as being the only celebratory male case he knew of.
Henry’s views on the portrayal of EDs was not just limited to men;

I get most angry when I think about the big narrative of it. It’s not just young females, usually in high school or college, who start to go bad. And, actually, in my experience there are obviously young females along these lines. But I’ve met older woman and it is like disorders because of abusive husbands or abusive parents, massive other problems (Henry Lines 592-96).

His thoughts show that Henry believed it is not just men who are disadvantaged by traditional ED stereotypes. Equally there are many different ways in which ED behaviours can be triggered. Henry’s views could also be a sign of his own low self-worth, as, in an interview about himself, he chose to be evangelical for others, perhaps indicating his own lack of importance. Henry felt that the stereotypical view of an ED (teenage girls) only made up 10-15% of the people with EDs he had actually encountered.

When asked his opinion on how he would change the portrayals of ED’s in men, his immediate answer of “I don’t think I could answer that because I’m just not aware of it,” (Henry Line 605) was the most revealing. For someone who has been in and out of treatment for over a decade it indicates how much work there needs to be done. When Henry further reflected upon this question his thoughts were that there needed to be a move away from the “superficial and cosmetic” (Henry Line 614). Which was interpreted as a desire to look below the surface of anorexia. “I think it’s a mental problem. I see it as a form of self-destruction; self-destruction is my own experience. It’s either control or self-destruction most of the time” (Henry Lines 619-21).

5.10.2 - CHARITIES

5.10.2.1 - Beat

Henry has been an active supporter of Beat, giving money to many of its campaigns. He believed that they do “good work” (Henry Line 726), but “it can be so much better” (Henry Line 745). On the whole, he was “dissatisfied” (Henry Line 730) with the charity outlining a number of areas of weakness. Firstly, Henry believed that Beat “skirts around this kind of stereotypical sufferers of eating disorders.” (Henry Line 730), meaning that the charity does not work to challenge the status quo to raise the profile of EDs as being more than non-teenage girls. Henry talked of the charity not having any geographical reach outside the South East, and coincidently believed that he would have received better
treatment if he lived nearer to Beat’s historical Norwich base rather than in the north of the country. His rationale for this was a belief that health services that are in close proximity to where the charity is based will be more aware of EDs. This is something that may be worthy of further investigation.

In addition to the above, Henry felt that the charity’s materials did not relate to him. Initially he called them “condescending” (Henry Line 747), before stating that it made him “feel alienated” (Henry Line 748), because “I just see lots of photos of happy young women, it’s all a kind of stereotype that kind of stuff” (Henry Lines 753-54). This again shows the recurring theme through his narrative of isolation and alienation that even exists within the ED community. In this case it is because he believes the charity, as with the health services, do not do enough to challenge stereotypes.

5.10.2.2 - MENGET

It would be no surprise if being generally dissatisfied with Beat would have led Henry to interacting with MENGET, as it is focused towards raising awareness of EDs in men. However, Henry said “I don’t know anything about Men Get Eating Disorders Too, I’ve never really tried to engage with them” (Henry Lines 721-22). Henry not engaging with MENGET is worrying, as it can be interpreted in a number of ways. Firstly, why had he not engaged with them, could they have come across as unappealing, unhelpful? Secondly, had experiences such as with Beat and his negative experiences with on-line forums have turned him totally away from engaging openly with a charity that is specifically aimed at helping men?

5.11 – KEY POINTS FROM HENRY’S STORY

- Personal and Background
  - History of mental illness in his family.
  - Serious health condition in his father.
  - Delayed puberty.
  - Felt his first ED behaviour was around 15/16.
  - Isolated socially and sexually (pre and post ED).
  - Felt shame about the illness.
- Rejected masculinity.
- **ED Manifestation**
  - Food restriction.
  - Exercise.
  - Laxatives.
- **Educational Experiences**
  - High educational achievement.
  - Lost control at university.
- **Treatment Experiences**
  - Never felt able to buy into treatment due to his gender.
  - Poor opinions of treatment and his treatment experiences.
- **Employment Experiences**
  - Unable to work full time.
- **ED Portrayals and ED Charities**
  - Felt ED portrayals to be non-existent in men and that charities could do better.

### 5.12 – REVIEWING HENRY’S STORY

Henry’s story highlighted a number of interesting experiences. The importance of his family being able to regulate his behaviour was interesting, as, alone, he seemed unable to control his ED behaviours. However, whether through the lack of opportunity or for other reasons Henry was able to control his behaviour much better when in the presence of his family. He showed a number of traits linked with anorexia, such as perfectionism and high achievement, whilst having extremely low self-esteem. Henry was isolated as a person which was exacerbated when in an ED cycle. It was clear that Henry’s experience of treatment was negative and gender stereotyping had played some part in that experience. Anorexia has played a huge part in his life and, with his inability to work full time, still did at the time of his interview.
CHAPTER 6 - MICHAEL’S STORY

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons
6.1 – OVERVIEW

Michael’s interview was via the telephone lasting approximately ninety minutes, including an off-record debriefing period forming no part of the research interview. At the time of the interview Michael was in his mid-thirties and had a near two-decade history of ED behaviour (food restriction and excessive exercise), experience and reflection.

At the time of being interviewed Michael appeared to have control over his life and was in a psychologically good place with a job he said he “enjoyed” (Michael Lines 429-30), and the love from his family and girlfriend. However, he identified that he was still not free of his ED,

“I won’t lie, I haven’t quite closed it. It’s still too current in my head and still governs the way I lead my life too much for me to say that” (Michael Lines 510-13).

6.2 – BACKGROUND

6.2.1 - FAMILY

Michael reported having an older sister and that his parents had been married for over forty years. He described his family as “very happy” (Michael Line 756) and defined himself as being “very white middle class” (Michael Line 775). Whilst growing up he did witness his mother being on diets and stated that he “was a little bit podgy” (Michael Line 191).

Educationally, Michael said; “I felt as if I was expected to go to university and be really good at school” (Michael Lines 759-60), however he stated that his family was not pushy which appears to be at odds with his previous statement. Michael believed that his education and the time he spent within it did have a part to play in his ED behaviour, but before examining this element of his life, Michael’s sexuality and his experience of relationships are important factors in helping to set the scene.

6.2.2 - SEXUALITY

Sexuality was in some ways an issue for Michael as he grew up, being socially isolated from his peers, partly through being bullied and partly due to his appearance. Michael felt
that because he did not attract any attention from girls, he may have been gay. He felt that people at school thought he was gay because of his shyness, but he also indicated that this may have continued into his adult life. It would appear Michael was using external influences as a guide to his sexual orientation, rather than trusting his internal feelings, the latter indicating self-doubt. In his twenties Michael’s libido, when present, confirmed his heterosexuality, and at the time of the interview he was in a relationship with a woman. However, with regard to his ED, Michael believed portrayals of male EDs gave the impression that all men who experienced this type of illness were homosexual. He said; “I’m sure the general public who don’t read xxxx and rarely raise issues like this probably think that it doesn’t affect men, and if it does, they’re all bent” (Michael Lines 985-88).

6.2.3 - RELATIONSHIPS

The “shyness” that Michael identified (Michael Line 226) is part of a chicken and egg situation, with feelings/emotions affecting his confidence within social situations, and consequences of this reinforcing his shyness. Michael’s lack of confidence was illustrated by comments such as “I don’t think anyone believes me when I say this” (Michael Lines 303-04) and “I am being 100% honest with you” (Michael Lines 519), both of which could have been trying to elicit approval from myself as researcher. The consequences of Michael’s shyness are that of isolation and low self-esteem. Michael’s shyness, low self-esteem and subsequent isolation are demonstrated in the extract below, where it is also evident that, on occasions, he may catastrophise situations and, as a result rationalise his behaviour;

There were a couple of girls at school that I quite liked but I was way too scared because what would happen if I went up to them and said ‘I really like you would you like to go out with me?’ They would obviously say ‘No! What are you on about? Get out of my face!’ and then I would get bullied for that and they would have people say ‘oh Michael’s after you’ that sort of thing. So why would I even put myself through that pain (Michael Lines 543-52).

Michael did not know they would reject him, but what it shows is that he is not able to take the risk of exposing his feelings, perhaps impairing his decision making regarding social connections. Michael’s first encounter with a female was in his early 30s, and after his
second bout of inpatient treatment. His encounter amounted to a kiss, which reiterates his lack of confidence and low self-esteem, particularly in forming relationships with women;

Between 18 and 30 [I] didn’t have the time, didn’t have the energy, really didn’t have the inclination. My libido was virtually non-existent and I still had the remnants of my school days where, as I said, I wore glasses, I was slightly overweight, I was a swat or I was perceived as being a swat, I was back of the queue and again I had no confidence in myself. I didn’t believe that any girl would want to go out with me, would want to kiss me or do anything, so I just didn’t even think about approaching anyone (Michael Lines 521-32).

At the time of his interview Michael was in a relationship. Talking about his girlfriend was perhaps Michael’s most emotional point during the interview; “She is amazing and extremely patient with me and is possibly too indulgent, too anxious to make sure that I’m not upset about anything.” (Michael Lines 501-03). At face value this may appear to be a supportive relationship, yet regardless of this, Michael is wary of his ED impacting on their relationship. In a following statement Michael clarified the relationship, stating; “But I try not to make it, we’re not quite living together yet, that will happen fairly soon, so I’m trying not to make it [the ED] impact too much” (Michael Lines 503-506).

The importance of having his girlfriend in his life is open to interpretation, but Michael’s statement of “I had no friends let alone a girlfriend” (Michael Lines 554-55), indicated that at some level he saw his relationship with her as being a sign of his recovery. Likewise, in a wider social context, it could be argued, Michael having a girlfriend might also reinforce his masculinity. His relationship and his girlfriend were extremely positive features in Michael’s life. At the time of interview, he had not made a commitment to living with her, and worried about how his ED if it came back as devastating as previously may impact on their relationship. In short it could be suggested that he was using the relationship as a positive tool against his ED.

6.2.4 - EDUCATION

Michael moved away from home to go to university where he attained his degree. Michael first sought help for his ED behaviour within six weeks of starting university, which may have been the result of moving away from home. However, he identified that he felt his behaviour started around the age of 16, whilst still in secondary school, although the seeds were sown much earlier.
Michael identified that he had been “bullied quite a lot” (Michael Line 126) when younger and this mainly revolved around his weight, having to wear glasses and his high educational achievements. His weight issue was most apparent during sport, which, although he enjoyed it, was not something he excelled in. This he believed was due to his weight, and as he eloquently said, it was a case of it being “pointed out to him” (Michael Line 195-196), rather than him thinking that he was overweight. When speaking of this, for me, it conjured up images of how, in the playground, this may have been pointed out to him!

Michael felt that it was at this point he understood the bullying would not stop unless he made changes, and the only thing he could change was his weight, prompting him to lose weight and exercise. The most telling comment by Michael in this section of the interview was him saying; “it was more me wanting to change it because of people’s reaction to me rather than any particular feeling that I’m particularly uncomfortable being the weight I was” (Michael Lines 200-03). This can be interpreted in many ways, one such way indicating that within Michael there was a need to be liked and/or conform to social expectations. People pleasing is a common trait among those diagnosed with anorexia (Treasure, 2005) and this interpretation of Michael’s actions is strengthened in that he found the positive feedback to his weight loss spurred him on.

Michael’s weight loss was not a panacea to a new life, although he received positive comments about his weight, including “Oh my God Michael you’re virtually anorexic now!” (Michael Line 215). He identified that there is much more to ‘Michael’ than weight loss;

People suddenly very positive. ...Certainly, definitely, no more attention from the opposite sex sadly! So, it wasn’t just weight as an issue, I was wearing glasses, I was very very shy and I was one of the brainy kids; I wouldn’t have approached a girl (Michael Lines 220-227).

Michael’s comments quite clearly indicate that a person with anorexia is much more than weight loss, suggesting that there are many inter-related complex issues inherent within an ED. Although his weight loss was experienced as a positive thing, it was only one aspect of his life that impinged on other aspects, such as developing his confidence and relationships.
When asked about any traumatic events in his life, Michael’s initial response was interesting: “Nothing particularly traumatic. I’m not sure if this really counts but I’ll bring it into the conversation” (Michael Lines 711-12). Which left me wondering why he needed to tell a story that he did not find traumatic. Michael proceeded to recall that when he was eight or nine, he was popular and had a number of friends, despite being podgy and good at school. He was “just one of the lads” (Michael Line 717). One day his teacher had to leave the classroom and asked him to write down the names of anyone who talked on the blackboard. Without question he did this and the people who he identified as talking were held back at break. “I didn’t question that my teacher told me to do it, and I’d always been told to do the right thing, and suddenly everyone started being really horrible to me” (Michael Lines 721-25). The fact that I had asked a question about traumatic events and Michael had answered by saying that he had not had any such experiences and then proceeded to tell the story, indicated that it must have had some lasting impact upon him. Perhaps this one incident was the catalyst for losing confidence and becoming isolated from his peers through allying himself with authority outside of his peer group. Rubin et al. (2009) indicated that isolation from peer groups in childhood creates a greater risk of issues such as anxiety, low self-esteem, depressive symptoms and peer difficulties.

Michael said; “I’ve had a lot of therapy and this is where I’ve linked it [his bullying] back to” (Michael Lines 713-14). In the immediate period after the blackboard incident Michael began to be bullied, so much so that he believes he withdrew in order not to be criticised, highlighting a further incident as an example. Michael had taken part and enjoyed being in a school theatre production (so much so that twenty-five years after the event he still remembered its name). However, when the school were advertising for people to be in a new theatre production Michael decided “I didn’t want to be in xxxxxxx because I didn’t want to be up there so people could pick on me or say ‘oh he’s rubbish’” (Michael Lines 734-36). Michael interpreted this as,

I had this sense, because of the bullying and everything else, I wasn’t quite up to standard. I had to gain other people’s approval or assurance. So, I think from that point I was always trying to catch up with everyone else and trying to make myself, just trying to get people’s approval which meant I was ok (Michael Lines 737-44).

Holding this sentiment and moving forward to his teenage years, when he began to gain positive comments from his peers due to him dieting, the need to be accepted and his
difficulty in being recognised within the mainstream becomes a strong argument for triggering his ED.

The need to be liked is another complex process. Looking back, Michael believed that at school he felt there came a point where his goal was not simply losing weight but he was "suddenly turning into a person trying to prove myself to be the fittest person and no one can pick anything out of that, so it was more about to do with avoiding any kind of criticism" (Michael Lines 361-65).

### 6.2.4.2 - University

On arrival at university Michael was able to be in total control of his food intake and, on a wider scale, his life. However, in contrast to this, Michael quickly lost what control he had at home, to such a point that within six weeks of being at university, and in poor health, he was diagnosed with anorexia.

Michael’s biggest regret about his university experience was that he; "didn’t try really to integrate with people" (Michael Lines 327-28), putting the blame for this firmly on his own shoulders;

Anorexia was almost a convenient excuse for me at university not to integrate, and not to go out and not to try and make friends with people if it meant I could just stay in my room every night and do what I had to do to satisfy the illness and persuade myself I was happy about it (Michael Lines 329-35).

This could be interpreted as being an example of Michael using rationalisation, a defence mechanism to explain his social isolation. Within his narrative Michael suggested he was isolated before the onset of his ED, and whilst this enabled him to remain isolated, it also prevented him from facing up to his underlying issues.

Michael finished university and got a 2:1 honours degree, he reported that he was “gutted” (Michael Line 309) with this grade. When asked how he would have felt if he had received a first, he said; "I think I would have just felt that I performed at par as it were" (Michael Lines 349-50). He continued, "I think if I’d have got a first no-one would have been able to pick up on that" (Michael Lines 357-58) indicating Michael might have been driven by the need to avoid a repeat of the criticism and rejection he encountered at school (Section 4.4.1.4.1). Michael himself linked his thoughts to this time;
It links back to that stage where my losing weight at school went from just losing weight to suddenly turning into a person trying to prove myself to be the fittest person and no one can pick anything out of that. So, it was more about to do with avoiding any kind of criticism, just in terms of if I had got a first, yes no one is going pick up on you only got it by 1% or something (Michael Lines 359-67).

Although one could suggest that even if he had succeeded in gaining a first by only 1% he still might have seen this as a problem, as he may have believed people would still be able to criticise him for not achieving 100%.

6.3 – ILLNESS

Chronologically Michael experienced symptoms and behaviours of an eating disorder for at least two years before starting university. He believed the main triggers for his ED stemmed from bullying but manifested from a number of related issues.

6.3.1 - MANIFESTATION

Initially when Michael decided to try and reduce the level of bullying he received, he felt that the only thing he could change was his weight. He started to do this by watching what he ate and by exercising more. Over time, this attempt at a healthy lifestyle change turned into the ED behaviour, whereby he started to restrict his diet more and exercise more extremely.

I had to change and the only thing that I could see about me being picked on that I could change was my weight. So, I took it upon myself to lose a little bit, eat a bit better and do some more exercise and I started getting back some positive feedback from that (Michael Lines 131-36).

Michael felt that the positive feedback he received on this weight loss was a factor in his crossing from healthy to obsessive behaviour.

It’s my theory that I latched on to that positive feedback and decided to keep it going, and that turned into being as fit as I possibly could and therefore being thin and everything, as that seemed to gain approval for me (Michael Lines 136-41).

As Michael lost weight at school, the bullying he received “tapered off” (Michael Line 227), perhaps in his mind reinforcing his acceptance by his peer group.
In hindsight, Michael felt it was around the age of 16 when his behaviour started to become more extreme. As previously quoted (Michael Lines 359-67), Michael said that he felt a shift in his behaviour from just losing weight to having to try to become the best at everything, thereby avoiding criticism. This desire to avoid criticism and to feel liked and accepted is clearly evident in men with anorexic tendencies (Andersen & Mickalide, 1983). However, a distinction at this point needs to be drawn between making changes in one’s life for a personal benefit which can be seen as being positive, as opposed to Michael’s case where he made changes largely to avoid criticism and to try and fit in. This was based on seeking the approval from others first; where there was no natural stopping point, as he could never in reality meet the approval of everyone. By judging himself on the reactions of others he in some ways ceded control of his destiny.

6.3.2 - THE SHACKLES COME OFF AT UNIVERSITY

Although Michael identified that his ED behaviour started before he left home for university, his behaviour worsened dramatically at this point. Michael stated;

> It was ok when I was at home because, as I’ve said, when I got to university I’d almost stopped eating pretty much, and then, as I say things declined rapidly and I was diagnosed within 6 weeks of being at university. And then it was 12 years of occasionally trying to do something about it most of the time, so I could live with it. And then 5 years ago I went to an in-place unit for the second time and something just clicked (Michael Lines 142-52).

While the above quote takes account of the trajectory of his ED both before and beyond university, it is evident Michael considers university as a key point in his illness.

From his narrative, it seems that even at home there were strong urges which he, for whatever reason, may not have been able to fully act upon. When talking about some of his behaviours when he first went to university Michael said; “I’d left home, one of the most important things to me was that now I could” (Michael Line 423-24). The “could” that Michael spoke of was the ability to weigh himself at every opportunity. Michael saw university as an opportunity, stating that at the time he felt,

> Right now, I can get really really fit’ there was a free gym, well not free it was £25 a year membership and sports clubs and all this free time when I could walk to university and I had power over what I ate completely (Michael Lines 252-55).
His use of the word “power” is evocative and illustrates the conflict between the person with the ED and food, the mind being at war with the body’s need for food.

Michael’s exercise regime involved circuit training amongst other things, as well as completing weekly bleep tests, with Michael realising “I was getting worse [at them] so I knew something wasn’t quite right” (Michael Lines 254-55). (Simplistically a bleep test is a measure of fitness often used in sports to quantify improvement or decline. The participant performs shuttle runs over a 20-25m course with the aim of being inside a bleep sound. As time progresses the interval between bleeps decreases and the participant has to run faster until they are bleeped out.) In his first six weeks away from home, Michael lost a stone and a half. Knowing there was something wrong with his health, and on the back of his behaviour at home, Michael commented “my parents had raised a little bit of concern” (Michael Lines 244-45). Also, due to his weight loss at university Michael said; “my dad had been trying to get me to go to the doctors because I think he was concerned about my losing weight” (Michael Lines 263-65). Michael did visit the doctors.

6.3.3 - SEEKING TREATMENT

When Michael went to see his doctor, he was diagnosed with anorexia. However, he had actually gone to see his GP because he believed that his health problems were due to him suffering from Meningitis. He stated;

I was getting worse so I knew something wasn’t quite right. I could see the weight going down and I had it; there were all these posters up around university (and I don’t think anyone believes me when I say this) and it was all about meningitis and there were all these symptoms; ‘are you feeling really tired? Is your skin looking terribly?’ And I was getting quite worried that I had meningitis or something (Michael Lines 258-67).

I found this comment interesting, as with a number of the men in the study, Michael had no conscious thoughts that his symptoms could have been attributed to an ED. When Michael saw the posters about meningitis he had his eureka moment believing that it explained everything. His comment within the above quotation “I don’t think anyone believes me when I say this” (Michael Line262-63) illustrates how EDs do not appear to be in the male psyche. Michael’s lack of attributing his symptoms to that of an ED might well have been due to the common misconception that EDs are specific to the female
gender, and therefore raises the issue of promoting eating disorders as illnesses that can affect anyone.

However, even though Michael explained his “symptoms” as possibly being meningitis, his thought process behind his actual visit to the doctors were much more complicated than previous paragraphs indicate.

I was on the way to xxxx to buy some weighing scales because I thought something is going on, but if I can weigh myself every day all the time I can keep track and make sure it doesn’t go down any lower. It was on this journey that I thought maybe I should go to the doctors to allay father’s concerns (Michael Lines 265-71).

Michael’s remarks in relation to the scales are somewhat confusing; in essence Michael was worried that he may have had meningitis. How he thought that by being able to weigh himself every day it would in some way alleviate the illness does not hold to any logic. One explanation could be Michael’s decision making and thinking may have been impaired due to his malnutrition (Keys et al. 1950; Treasure, 2005; Tchanturia et al. 2012). Alternatively, Michael may have been in denial of having an ED but could better cope with having a physical disorder which perhaps is less stigmatising (Stewart, et al., 2008). Indeed, both Stewart et al. (2008) and Roehrig and McLean (2010) found stigma was higher for people with EDs than with depression. Michael went on to say, “I got there and within five minutes the doctor was mentioning the word anorexia which was the first time it had ever occurred to me.” (Michael Lines 271-74)

6.3.4 - TREATMENT CHRONOLOGY

Michael’s story of his treatment is especially interesting. It ranges from experiencing treatment in different geographical locations, both private and statutory, and having inpatient treatment in response to a number of relapses

Michael categorised his treatment into four episodes of his life and three distinct phases of treatment. Whilst his narrative on this was clear, what came back when reading the transcript and listening to the interview recording was that his description of treatment was un-emotional and detached, as though speaking of a third person, a factor reported in other studies (Schmidt and Treasure, 2006).
6.3.4.1 - Episode 1 University, Treatment

After Michael’s initial consultation with the university Doctor in his first term he was referred for therapy which he received within three months. This referral might be considered as quick, and this could have been for a number of reasons. Michael’s choice of university for his study was fortunate as it has a number of ED researchers, as well as being tied to the local NHS trust which had an established ED service. However, this would imply, whether conscious or unconscious, Michael having some level of awareness of his ED, prior to making his choices for university, which he said he did not. In contrast, it could also have been the result of Michael’s weight loss being deemed to be severe.

Michael had a series of weekly CBT therapy sessions which saw him regain weight and, by his third year at university, he was allowed to cycle and use the gym. Michael said; “physically I did start to improve but that again was very very difficult as I was still in charge of what I was eating” (Michael Lines 291-93). His overriding comment with his initial experience of therapy was “nothing really was done to tackle what it was that was going wrong” (Michael Lines 296-98), indicating that the focus of the therapy was on weight and targets associated with this, and as Michael achieved these goals he was allowed to undertake physical exercise again such as cycling. At the end of his studies Michael went back home to his parents and had a year where, presumably not having full control over meals, he seemed to live normally.

6.3.4.2 - Episode 2 Bright Lights of the City

Michael’s second episode began when he left home for the second time to work in a large city, a time when he thought that he was healthy and had been “cured”. However, as he reported, “I was back in charge of my life, things started to spiral downwards a little bit” (Michael Lines 795-77). A free gym at work did not help him where he was able to exercise excessively. From here he moved to a completely different area of the country and his condition worsened. Why he moved was not ascertained during interview. However, this move did not see an improvement in his health. In fact, it resulted in a continued decline, whereby over approximately one year, with concerns raised again by his parents and his own thoughts, he booked into to see his GP and was again referred to an ED unit. Again, Michael was fortunate that he was in a location with a specific ED unit.
6.3.4.3 - Episode 3 Insider Information of Treatment and Care

Therapy as an out-patient continued for approximately one year, but it was not successful, and Michael found himself being hospitalised for the first time. When reflecting on this Michael recalled how; “[he] really enjoyed it, loved being the only man on the unit, got all this female attention for pretty much for the first time in my life” (Michael Lines 809-11). The latter part of this statement perhaps indicates how important it was for Michael to be recognised and given female attention. As human beings, having recognition from others as a person is important for self-esteem (Silvera, et al., 1998), with Silverstone (1992) arguing that low self-esteem is a pre-requisite to an ED. With regard to his increased esteem, Michael went on to say; “Everything I felt was really positive, I had put the weight back on, it’s very controlled” (Michael Lines 812-13). However, his next sentence was more revealing “but now I look back I didn’t really do anything seriously to sort out the issues behind it” (Michael Lines 814-15). Whilst this could be interpreted as there being a focus on weight gain and not on the underlying issues troubling Michael, it could also be the result of Michael not wanting to engage in therapy as he may well have found dealing with certain aspects of his life too distressing. Michael’s inpatient treatment lasted for three months, at the end of this period with his weight being “acceptable”, he was discharged back into outpatient treatment.

6.3.4.3.1 - A Brilliant Twelve Months?

Michael’s next passage of life, after his discharge from inpatient treatment, he described as; “I had probably about a year when everything was brilliant” (Michael Line 815-16), which on the face of it would seem to be extremely positive. However, Michael’s full quote was;

I had probably about a year when everything was brilliant and the weight is going down slightly, but nothing too concerning. I had made new friends at the unit, I kept seeing them afterwards and I had this major idea to quit my career and become a mental health nurse as I had been so inspired by the people in the hospital. And then just after that year it just completely went again (Michael Lines 815-23).

While the construction of Michael’s statement starts off demonstrating positive thinking, he reverts to his more familiar negative belief about self, suggesting the optimism was then lost. Ignoring his weight loss could be seen as Michael engaging in denial. The wording of
this statement indicates that although he put weight on in the inpatient unit, his underlying distress could have compromised his conscious willingness to get better.

The controversial nature of his ‘brilliant year’ was further explicated by Michael stating; “I had been receiving outpatient treatment, but that stopped because I wasn’t going anywhere and I was wasting their time” (Michael Lines 823-26). The treatment stopped, but it is not clear as to who instigated this. What is telling is the dialogue about “wasting people’s time” with this being akin to people pleasing traits, low self-esteem and their commonality in those with EDs (Treasure, 2005).

6.3.4.3.2 - No More; There Is No Point

“At that point, I think I just accepted that it was going to be in my life forever, there’s nothing I can do about it so I just wanted to manage the situation as best I could” (Michael Lines 827-30). Michael’s management of the situation resulted in his weight dropping to a point he described as “ruining his life” (Michael Line 832). His belief in becoming better and confidence in the health professionals’ ability to help was non-existent, “I didn’t see the point in therapy because if the unit at the hospital hadn’t sorted it what was the point of trying again, it's just a waste of time” (Michael Lines 832-35). The latter is indicative of pessimism and perhaps demonstrates the physical and psychological burden Michael was living with.

6.3.4.4 - Episode 4 Last Chance Saloon.

A period of 2-4 years elapsed between this phase and the previous phase of his illness. Michael tried to manage the ED, but he eventually decided to try and get help again when “a spark in the back of my head said that it was worth one more go and possibly because my life had become so appallingly sh*t” (Michael Lines 836-39). The latter part of the statement suggested emotional turmoil in keeping with despair. A visit to his GP saw an immediate referral to the inpatient unit and four months of inpatient treatment which perhaps indicates the level of despair felt by Michael.

At the time of Michael’s interview, this bout of inpatient treatment (discussed above) was the last that he had received. He was in his late twenties and it was approximately ten years after first seeing the GP at university. Michael described how, during his previous
treatments, he never felt that he addressed his underlying issues. His maxim in this bout of
treatment was;

I hadn’t sorted out all the stuff first time around and I felt this was the last chance
so I made damn sure that this time I would do as much as I could and change and
do everything that I didn’t do the first time and try and sort out the long-term
issues (Michael Lines 842-47).

This perhaps indicated that at this time he was in the correct mindset and perhaps
unconsciously he was ready to let go of the illness. It may also indicate a growing maturity
to take more control over his treatment direction and look at issues rather than weight. This
would be in keeping with Wooldridge et al. (2014) who suggest when the focus is on
weight gain alone it can alienate patients as their problems are not being dealt with.

Another important change seemed to be that whilst Michael wanted to target his long-term
issues, so did his therapist, “I got another therapist who was outstandingly brilliant and
kind of worked with me on the long-term issues” (Michael Lines 847-49). This statement
reinforces the importance of the practitioner/patient therapeutic relationship, particularly
when exploring sensitive issues (Warne and McAndrew, 2007; McAndrew et al., 2014).

6.3.5 - EXPERIENCES OF INPATIENT TREATMENT

Michael, as discussed above, had two episodes of inpatient treatment and when asked to
describe these experiences his initial response was totally descriptive;

In my case it was being the only man in an all-female unit. Having three meals a
day plus snacks. Not being allowed to go out, not being allowed to walk round the
unit or do any exercises until you’ve reached a certain weight, at the same time
doing a variety of sessions with the group and other patients (Michael Lines 858-64).

Whilst it is interesting from the point of view of what went on during his stay on the unit,
it did not provide insight with regard to how these experiences impacted on him as a
person. However, he did describe some of his feelings and talked of his sense of relief that
he was no longer in control of his life and was therefore not responsible;

It took the responsibility of my life essentially away from me, so when I was
living on my own at home whatever I ate was my fault, it was my responsibility.
Whatever exercise I did was my responsibility whereas when I was in hospital I
wasn’t allowed to exercise, these nurses were not force feeding me, but putting
food in front of me and I had to eat that before I could go (Michael Lines 867-75).
The quotation from Michael’s transcript is interesting as the literature suggests that, characteristically, those diagnosed with anorexia are often rigid in their thinking and there is strong adherence to their rules (Murray, et al., 2014). Given his experiences of being an inpatient challenged his rules and thinking, one would expect this would have been a stressful and difficult experience for Michael. However, Michael appeared to be accepting of the challenges, perhaps indicating his subservience through low self-esteem (Schmidt & Treasure, 2006). In his own mind Michael was unsure why he was able to cope with relinquishing control to the staff in the hospital;

I don’t know quite why as a lot of people can’t cope with it this way, it wasn’t my fault anymore. I couldn’t do anything about it; it was being done to me. A lot of people with this illness cannot cope with it at all (Michael Lines 876-81).

He then went on to explain his acceptance;

For me it was almost like a holiday from the illness, my life. It was 4 months of suddenly not having this guilt of being amongst people, being forced to be with people when I just wanted normally to shy away from them. And suddenly because the one thing in real life that distinguished me was my illness, that’s the one thing that distinguished me from everyone else, suddenly I’m in this environment; that the one thing that doesn’t distinguish me is the fact that I’ve got an eating disorder because everyone’s got it (Michael Lines 882-93).

For Michael being in the inpatient unit made him feel normal, everyone had an ED, he did not have to hide his illness and he could be himself, showing parts of his character that he had suppressed. His inpatient experience allowed him to get positive feedback based on him rather than, as had happened in the past, for losing weight. “It just showed me that there is more to this, you know me, than the illness had ever let me see.” (Michael Lines 900-02) Another aspect of Michael’s experience of inpatient care was that he witnessed a number of people being treated who were in denial of their ED or struggling to cope. He said "most of them go to lengths that I would never even conceive of to protect their eating disorder and keep it going” (Michael Lines 892-95). This statement might give some indication of Michael’s motivation to recover from his ED.

6.3.6 - A TWO-WAY STREET TO HEALTH

In any illness, the patient clinician relationship plays a pivotal role; treatment is only as good as the clinician’s skill and patient’s willingness to engage through the desire to
recover. If one party fails to commit, the relationship and subsequently the outcome will be compromised (McAndrew et al., 2014). Michael appeared to be aware of how such relationships work; “it doesn’t matter how many wonderful therapists you’ve got and how many wonderful plans that are set out... if you really don’t go for it, it won’t work in the long term” (Michael Lines 911-15). This sentiment was further exemplified when Michael talked of how he initially compromised his recovery and latterly took responsibility; “I wasn’t going anywhere and I was wasting their time.” (Michael Lines 825-26). When talking about stopping therapy; “The first hospital I put on the weight but I didn’t really work with addressing the issues behind it” (Michael Lines 915-17) and latterly; “I did the things and did the work that I didn’t do the first time” (Michael Lines 921-23).

Michael stated; “the illness made me stop wanting the nursing” (Michael Lines 826-27), transferring “blame” for his lack of engagement onto the illness which he detaches from self. While Michael takes on responsibility for compromising his treatment, it is not clear what opportunities he was given for addressing the underlying issues. On two occasions Michael directly spoke about therapists. Initially Michael made reference to a therapist he had at university, “nothing really was done to tackle what it was that was going wrong” (Michael Lines 296-98). In contrast, when discussing his second experience of inpatient treatment, he said; “I got another therapist who was outstandingly brilliant and kind of worked with me on the long-term issues” (Michael Lines 847-49). The interpretation from this statement is that Michael’s previous therapists for one reason or another did not explore long term issues with him.

6.4 – THROUGH THE LOOKING GLASS REACTIONS TO HIS ED

6.4.1 - MICHAEL’S REACTION

When Michael spoke about his reaction to his diagnosis of anorexia he spoke of thoughts such as; “what is the doctor talking about, I’m not anorexic I don’t know what she is talking about” (Michael Lines 460-63) and “What no chance, I’ve got meningitis” (Michael Line 1069). His disbelief was reinforced by stereotyping and denial “This is an illness that silly little girls get that don’t eat enough, I’m eating loads!” (Michael Lines
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An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or atypical anorexia/EDNOS

Gareth Lyons
**6.4.3 - FRIENDS’ REACTIONS**

The reaction of Michael’s friends where he grew up, he believed was good. However, he described how, whilst showing their concern, they tried to get him to eat more, an action, which is not necessarily helpful (Treasure, 2005). Although his friends reacted positively in terms of wanting to help, Michael’s next statement was surprising on a number of levels. “I still don’t think I’ve ever had a conversation with them about it, whether perhaps that’s because we’re men and we don’t, but I still don’t really know their perspectives, part of me wishes I did” (Michael Lines 477-81). Whilst masculinity is often a barrier to male health care, research (Cooperman, 2000; Morris, 2006) has shown that exposure to health problems leads to awareness. In the case of Michael’s friends, it seems their exposure to his ED did not prompt any further interest to find out about it. It was only after Michael did some exploratory work around EDs that some of them said that they did worry about him, with one apologising for taking part in some of his bullying. Michael attributed this inability to discuss sensitive topics as “that’s what men do I suppose!” (Michael Lines 486-87).

**6.5 – THE INFLUENCE OF LOVED ONES**

When Michael first sought help at the age of 18 it took him roughly 12 years to get to a place where he felt the ED was past him. In that time, apart from holidays during university, he has only lived for approximately one year at home and it appears from his narrative the rest of the time has been spent largely living an isolated life. When Michael started university, he was diagnosed with an ED after only six or so weeks despite having experienced ED behaviour for two years. Michael said “It was ok when I was at home” (Michael Line 142) ... “when I was at home my mother was still cooking for me so there was some kind of brake on the eating disorder” (Michael Lines 292-94). Michael’s parents appear to have mediated his illness; his mother cooking for him could be construed as him not having control of food, similar to his experience of being an inpatient, while the main reasons for initially going to the doctors was to “allay father’s concerns” (Michael Line 317). Furthermore, his year after university spent at home resulted in Michael stating; “I wasn’t getting any treatment at this point, I thought I was fine, I thought I had been cured” (Michael Lines 839-80). This indicates a link between a safe environment and ED
behaviour. Although it must be made clear that this does not necessarily mean an absence of ED behaviour, as before Michael left for university he was engaging in ED behaviours, but there was a “limit” to what he could do.

The influence of Michael’s girlfriend was an unknown yet listening to the emotion in his voice and looking at his transcript one cannot help but wonder if her presence in his life was a protective factor, akin to a surrogate parent who could take control from him. Michael had spent so much of his life in isolation and thinking negatively about himself, to have someone who loved him and wanted to spend time with him could be invigorating, as well as a little frightening. When Michael said “I’m trying not to make it impact too much,” (Michael Line 551-552), it could be seen as one human being not wanting to cause potential pain on another. However, it could be suggested that the ED provides relationship roles for them, a patient and carer, akin to Berne’s (2016) transactional analysis parent-child relationship.

6.6 – MICHAEL’S EXPERIENCE OF ANOREXIC EFFECTS/TRAITS

6.6.1 - PSYCHOLOGICAL

Despite the ED, Michael completed his degree with a 2:1 and his reaction to this was an example of the perfectionism attributed to many people with EDs (Andersen and Mickalide, 1983; Treasure, 2005). “I managed to keep going and I got a 2:1 and I was absolutely gutted with that, and I didn’t think that having an eating disorder for 3 years was really any excuse for that” (Michael Lines 302-05). When asked about how he felt about this now in his mid-thirties, he responded by stating he did not feel as bad about it now. However, he went on to say he had been very close to achieving a first and said “if I had made a couple of better choices on the modules that I did, I probably would have got a first” (Michael Line 319-21). This comment was extremely interesting and can be interpreted in many different ways, with one such way being that he still makes no allowance today for the effects of the ED; it was his fault he did not achieve a first and nothing to do with the illness.
Michael reported that, when engaged in his ED behaviours, it was all consuming “it’s your entire existence pretty much!” (Michael Lines 665-66). Examples of this can be seen throughout his transcript;

The only way that I could control it [anorexia] was to live my life like that checking my weight so damn often. (Michael Lines 623-24)

If someone offered me a crisp and I would be beside myself with worry until I had weighed myself to make sure that hadn’t tipped the balance... (Michael Lines 627-31)

Every tiny little increase is an absolute disaster and it’s going to send you rocketing from 6 stone to 16 stone by the next morning (Michael Lines 614-17).

Reflecting upon this behaviour Michael said “with all that crap going through your head how you do anything is amazing, how did I get a 2:1? How did I manage that?” (Michael Lines 576-87). Michael was asked if he felt the ED had affected his mental abilities, to which he answered that he felt in some ways it had. At the time of his interview in his mid-thirties he stated that the ED had left him “knackered beyond belief” (Michael Line 657). He also felt that his thought processing had been affected, adding that he did not feel his brain was as sharp as it was in his earlier life.

Whilst actively engaged in his ED behaviours Michael said he; “didn’t really have any room in my head for anything other than the illness” (Michael Lines 659-60), indicating that all processing and thinking was at times affected. However, he did concede that during his studies; “the one thing an eating disorder gives you or at least emphasises is drive” (Michael Line 670-71) to achieve. This is in keeping with the literature which indicates perfectionism and high drive as risk factors in terms of EDs (Treasure 2005).

Continuing upon this theme Michael was asked if he felt his ED had resulted in increased impulsivity, as noted by Claes et al. (2012a) and Tchanturia et al. (2012). Whilst he initially felt he did not see any increased impulsivity, he did state that after a bout of treatment he stopped his career and enrolled on a course to become a mental health nurse. This was an impulsive decision which involved quitting his job and thereby stopping his income stream. Another impulsive decision ended his mental health nursing course, Michael stated; “one day I just decided to stop doing it [the course] and that was linked to the illness. So, I was capable of just jacking it all in” (Michael Lines 621-24).
EDs are often linked to ritualistic and obsessive behaviour. Michael stated; “I had a routine, a list of things that I had to do, so if everyone was going to impact on that I would cut short a conversation” (Michael Lines 634-36). For example, Michael cited occasions where he would become agitated at being unable to exercise. Even at a point in his life where he is happy (at the time of the interview), Michael stated that “I feel I have to go for a walk after eating my evening meal” (Michael Lines 490-91) ... “I feel I have to do it to feel comfortable” (Michael Lines 498-99). This is suggestive of it being ritualistic, rather than something he does for pleasure. His girlfriend accompanied him and when he was asked if this was to stop him overdoing it, Michael indicated this was not the case; “she spends all day indoors so she quite enjoys coming for a walk and I don’t go for a two hour walk or anything, and if it’s rubbish weather she doesn’t bother coming with me” (Michael Lines 501-04). The fact that Michael’s girlfriend did not accompany him on his walks in bad weather, suggested that he goes out in all weathers, indicating a level of obsessive behaviour. Michael felt that whilst not an aggressive person, he did feel a change in his behaviour especially when challenged about his ED; this would result in him changing conversations or getting angry.

6.6.2 - PHYSICAL EFFECTS

Low libido has been attributed as an effect of starvation (Keys, et al., 1950) as well as within EDs (Hall et al., 1985; Treasure, 2005; Agalusca et al., 2012). Michael stated that between the ages of 18 and 30 he largely did not have a libido which was in-keeping with literature, “didn’t have the energy, really didn’t have the inclination, my libido was virtually non-existent and I still had the remnants of my school days where, as I said, I wore glasses I was slightly overweight” (Michael Lines 528-32). Within his quotation Michael introduced a psychological, as well as physical element (glasses and weight), into his lack of libido; this being that because of his belief as to his lack of physical attractiveness there was no need for him to have a libido, which could be described as regression.

Michael also suffered for a time, because of his low weight, from osteoporosis which he said had been corrected after his diet improved. Michael also added that his height was three inches below what he been estimated as a child; he did not know if his anorexia had
had anything to do with this. However, Modan-Moses et al. (2003) found a correlation between stunted growth and anorexia in male adolescents. Michael also commented on experiencing a lot of bowel problems, which he said could be IBS (although it was not clear if that was his diagnosis or his doctors). Interestingly Michael was not sure if this was connected but felt that the time between his ED stopping and his bowel problems starting was too much of a coincidence. There is some justification in this as there is evidence to suggest that after recovery from an ED, problems in the gut, heartburn, indigestion, stomach ulcers and irritable bowels are common (Treasure, 2005).

6.7 – THE MEDIA

Michael, like a number of men in the study, was actively involved in raising ED awareness. He felt that over time media coverage has improved and he felt that both MENGET and Beat do good work. However, he did feel MENGET was focused too much on the area around its Brighton base, and he was critical of a video Beat commissioned to highlight male EDs. This particular video showed a man ‘vomiting up his testicles’, allegedly depicting lost masculinity, but the video was dropped after criticism. Michael thought that Beat needed to look at how it portrayed male EDs after this episode. He highlighted his own direct negative experiences of the media;

I’ve been asked by a magazine would you like to do an interview and do you have any photographs of when you were ill? That annoys the hell out of me because they’re not particularly interested when I say ‘no I haven’t but do you want to hear why I haven’t?’ (Michael Lines 1167-72)

Whilst he could see that there needs to be an element of sensation to make the story interesting, he felt the desire to see images would sensationalise too much and was in contravention of Beat’s media guidelines.

6.8 – DON’T LOOK BACK IN ANGER

In the final section of Michael’s interview, he reflected on how much of his life he felt he had lost, but considered that “In some ways it was sort of interesting to go through it but I wouldn’t recommend it to anyone” (Michael Lines 1344-46). Michael said that he did not regret having anorexia and had ceased to get angry about it. However, the impression
gained from his narrative was that whilst he was happy imparting some information, he was still guarding his emotions and deepest feelings. Given this was a telephone interview with someone he had never met this was understandable. It may be that his feelings have been suppressed, although when directly asked about his emotions his response was to speak about other people’s views. This was illustrated in his comment in which he said of his ED “I haven’t quite closed it. It’s still too current in my head and still governs the way I lead my life too much for me to say that.” (Michael Lines 471-73). A comment which adds weight to the theory expressed previously in this analysis, at some level having found someone to share his life with, he was worried that a return of his ED would lead to isolation again.

Michael also showed a great deal of compassion for the people he had encountered during his experiences, and because of this he felt EDs, and not just male ones, could be improved in a number of areas. Firstly, he believed we should be aware that they exist. Secondly, he felt that “the general view of eating disorders being about young wealthy girls wanting the attention is hugely, I’m not sure if damaging is the word, but really dangerous, but not just for men but also for older women” (Michael Lines 1091-95). He said “I’ve been there [hospital] with women who are over 70. I’ve also heard of men being over 70” (Michael Lines 1105-06) ... “it can hit absolutely anyone and it will rip apart your life regardless of how much money you’ve got.” (Michael Lines 1115-17)

The penultimate words of Michael’s used in this analysis are the most telling and chastening “this illness doesn’t discriminate and doesn’t care if you’re a man or a woman, whether you are old or young,” (Michael Lines 1110-12). This was a call to arms for all to challenge stereotypes and move knowledge forward for all. His final words tell of the unpleasantness of his experiences, “I would not wish this on my worst enemy” (Michael Lines 1351).

### 6.9 – KEY POINTS FROM MICHAEL’S STORY

- **Personal and Background**
  - Overweight growing up.
  - Mother history of diets.
  - Isolated and shy growing up.
- Felt unattractive to females and questioned his sexuality.
- Bullied at school, due to his weight and academic prowess, which he felt started after one specific incident aged around eight or nine. (outside of his peer group).
- Consciously felt his first ED behaviour around the age of 16, however previous to this were episodes of dieting and healthy eating in order to stop/reduce bullying.
- Unemotional and detached when talking about his treatment experiences.
- Changed career and then changed it again which shows impulsivity.

- ED Manifestation
  - Food restriction.
  - Exercise.

- Educational Experiences
  - Lost control at university.

- Reactions and Treatment Experiences
  - First time he thought he had an ED was when diagnosed.
  - He felt he had a number of bouts of his ED because he/his carers never tackled his underlying problems and only focused on weight until his last bout of inpatient treatment.
  - Felt masculinity hampered his male friends’ reactions.

- ED Portrayals and ED Charities
  - Felt portrayals of ED in men emphasise gay men.
  - Angry at portrayals which show EDs as an illness of young women only.
CHAPTER 7 - STEPHEN’S STORY

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons
7.1 – QUESTIONING THE INTERVIEW

Stephen’s interview was interesting on a number of levels. This was an email interview with no other contact, and thoughts crossed my mind both during and post interview as to who Stephen was. They ranged from one extreme to the other. Was he someone who was extremely isolated and lacking in confidence or trust? Or was he to put it simply a fraud, a time waster or someone with different mental health issues? An article in the Guardian by Jenny Kleeman (2011) kept springing to mind. The article was titled “Sick Note” and described the growing number of people who fake illness via social media and forums. The level of detail and the effort that goes into creating and maintaining identities takes this away from the level of internet trolls and is seen by some as an extreme need to get attention. Indeed, Kleeman (2011) wrote that it had been labelled Munchausen by Internet (MBI). Another newspaper article (Buckland 2010) reported on a survey of a counselling website claiming 34% of teenagers had lied about having a mental illness to look fashionable, with eating disorders being the most popular phantom problem. Combining these two articles, even though they may be discredited because they are not academic, planted thoughts in my mind which were remembered during my analysis of Stephen’s interview. It made me question if Stephen’s interview lacked the level of depth of the others because he was “a fraud” in terms of having an ED and did not want to be caught out. I did not think so at the time, and in hindsight I believe he was genuine, this opinion being based on my own ED experiences, as well as the experiences of some of the other men interviewed. Furthermore, from a practical level, if Stephen was a fraud I am sure, having gone to the effort of taking part in the study and researching EDs, he would have provided much more information about his “experiences”

7.2 – THE INTERVIEW

At the time of Stephen’s email interview, which took place over a couple weeks, he was in his early twenties, and reported a lifetime of issues around food “I have always had issues with food ever since I was weaned; food was never something I had much interest in.” (Stephen Lines 9-10). He was diagnosed with anorexia at the age of 14 and his behaviour during his ED revolved around food restriction only.
7.2.1 - BACKGROUND

7.2.1.1 - Family

Stephen’s immediate family was made up of his sister, mother, father and step-father. When his parents split up was not ascertained. If it was not before his ED it certainly was during the first four years of his illness, as he wrote; “For the first four years the only people that knew were my Mum, Dad, Step Dad and Sister as I didn’t want everyone getting involved” (Stephen Line 29-30). If Stephen’s parents split up after he was diagnosed, it begs the question of his illness being a factor. Stephen was asked directly if he thought his parents splitting up affected him. His response of; “not really, it made me much happier” (Stephen Line 159) was extremely candid, and could easily be construed that he is somewhat unfeeling or selfish (a stereotypical negative trait often associated with people diagnosed with anorexia (Treasure, 2005)), or it could simply be the separation of his parents was a release of tension and stress at home.

Stephen reported that “most of my family are overweight” (Stephen Line 162) although he did not specify who, and that “most have depression etc” (Stephen Line 164) again not saying who was ill. These comments were broadly in line with the findings of Crisp et al. (2006) who noted the prevalence of mental illness in families of males with EDs.

7.2.1.2 - Growing Up

Stephen reported as stated in the overview to this section, that he has always had problems around food. He also stated that as a person he felt isolated from others, and his ED, he felt was due to bullying and low self-esteem. “I know for me that my main cause was bullying which I had experienced all of my life leaving myself with very low self-esteem” (Stephen Lines 21-22). The bullying revolved around how he looked; “mostly my teeth sticking out and shaved hair. I was mostly called names, but also used to get slapped round the back of the head and called slap head” (Stephen Lines 111-113). This may in some way explain Stephen’s isolation, as the bullying put him outside of the acceptable masculinities when growing up. If Stephen did not confront the bullying in an ‘acceptable male way’, with aggression, it could have caused him further torment psychologically. Whilst withdrawn, Stephen would have not faced his bullies physically, but his low self-esteem might indicate the psychological trauma caused by the bullying. When analysing this section of Stephen’s
An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or atypical anorexia/EDNOS

transcript Hemmingway’s (2005) portrayal of Pablo in “For Whom the Bell Tolls” sprang to my mind. Pablo deserts his comrades in the face of what he believes is a suicide mission, but returns as he cannot face his living with his mind’s recriminations and the knowledge of running away, whilst his friends die. It is obvious from Stephen’s story the experience of being bullied was still evident, as he wrote; “most of my feelings I have blocked out, but it still sits there and haunts me.” (Stephen Line 115)

7.2.1.3 - Education

On his demographic questionnaire Stephen ticked that he was a graduate. However, of the men interviewed for this project, his experience was slightly different in that his ED behaviour was identified and brought to the attention of the health care system whilst he was in secondary school. Stephen stated;

I definitely feel my education was hindered by my eating disorder as I did alright in them [exams] but I could have done better. But I had so much going on that it was difficult to concentrate on it all and I didn’t have enough support in my education throughout that time (Stephen Lines 36-38).

When asked to clarify what he meant by not having enough support he wrote “my school knew, but didn’t understand or know what support I needed to help me” (Stephen Line 130). Stephen thought his gender was an issue, as the school was not equipped to deal with it (his ED) or him. Worryingly, Stephen’s experience was relatively recent, around 2006. Stephen did receive help from a school counsellor but this in itself was self-defeating as to see the councillor he had to do this “during lessons so I’d miss out on schooling” (Stephen Lines 230-31). From an educational point of view taking a pupil out of a classroom on a regular basis could quite possibly hamper their education especially if it was at a regular time. In Stephen’s case this would have been during his GCSEs (age 14-16). Additionally, it could be suggested that removing a person who experiences a high level of bullying from a classroom for “special treatment” would potentially lead to further bullying.

Stephen wrote that he would miss out on schooling, but he did not clarify if he believed this to be a positive or negative experience.

7.2.1.4 - Eating Disorder Manifestation

Stephen’s eating disordered behaviour revolved solely around the restriction of food. He stated that he managed his behaviour to go undetected because “the habits I kept from my
parents were mostly not eating my lunch at school, which is how they didn’t notice at first” (Stephen Lines 103-05). Unfortunately, this kind of behaviour can lead to people labelling those with an ED as being selfish and/or deceitful. Stephen wrote in his opening answer to the first question that he had always had issues around food, which he elaborated upon later as “fussiness” (Stephen Line 101) and “struggling with making decisions around food” (Stephen Line 50). This remains current for Stephen, where expanding his diet with new foods makes him “anxious” (Stephen Line 117).

7.2.2 - REACTIONS TO HIS EATING DISORDER

7.2.2.1 - Stephen

Stephen’s reaction to the news of his eating disorder was extremely interesting. When told by his mother that he was going to the doctors he wrote;

I didn’t think there was anything wrong with me, so I didn’t think it would be an issue. It wasn’t until I got there and started going over everything that I started to realise that what I was doing wasn’t normal and then it was all just a blur and I broke down crying (Stephen Lines 12-15).

It seems from this statement that Stephen did not think he had any problems before his behaviour was explained to him. He is in some ways lucky that he accepted his doctor’s opinion at the first consultation. Stephen later wrote, “I was very upset, but in some ways relieved as it finally made everything make sense” (Stephen Line 107). Stephen articulated his reaction whilst sat in the car immediately after seeing the doctor; “I couldn’t stop crying, that word [anorexia] made everything fit together and make sense as to what I was doing” (Stephen Lines 16-17). This indicates a release of his emotions and his understanding, perhaps demonstrating at an unconscious level he knew his behaviour was not healthy.

Stephen wrote of his eating disorder that he “was a bit embarrassed” (Stephen Line 122), which in itself is interesting and leads to much conjecture as to why. It could be related to having a mental illness, which is identified as being debilitating for men (Courtney 2000). Stephen also had to contend with delayed puberty, which could cause further embarrassment, especially in the sexualised world we live in and the connotations related to EDs in men (Fichter and Daser, 1987; Bassett, 2002; Robinson et al., 2012). Stephen’s
embarrassment was reiterated when he said; “I didn’t want the hassle of all the questions and people trying to help when actually making it worse,” (Stephen Lines 121-22). Such embarrassment could have also perpetuated his isolation, as for the first four years of his behaviour only Stephen’s immediate family, his mother, father, step father and sister, were aware of his ED. Another reason for not wanting people to know about his ED was that he believed it would create “nit picking and could also open it up to more bullying” (Stephen Lines 216-17). This was a sobering statement, again showing the effects of the bullying upon him. Looking back at his behaviour Stephen wrote that it “horrified him” (Stephen Line 26). When asked to clarify what he meant he wrote; “It’s more the disbelief at what I used to do and not being able to compute why I did it” (Stephen Line 118).

7.2.2.2 - Family Reaction

Stephen’s mother, stepfather and sister responded to his eating disorder positively, Stephen stated; “they couldn’t of (sic) been more helpful and I couldn’t of (sic) gotten where I am now without them.” (Stephen Lines 30-31). His mother and stepfather seem to have been the driving force behind Stephen going to see the doctor for help. In contrast, Stephen’s natural father was in his words “a nightmare” (Stephen Line 32), who tried to help by refusing to let Stephen leave food on his plate at meal times. When asked about this behaviour Stephen explained that he believed his father did not understand how the ED works and that he is “of the age where a man is a man and you get on with things and don’t show feelings” (Stephen Lines 124-125). At the time of interview Stephen had never spoken to his father about this, perhaps indicating both men’s perceptions of masculinity, and/or for Stephen it may have caused his experience of bullying to resurface (Blaauw, 2002).

Stephen’s natural father’s response is not uncommon. The behaviour of making Stephen sit at the table until his meal is finished is not helpful, confrontational and an opposite of that suggested by Treasure et al. (2009). This exemplifies that we often focus on the person with the illness/problem and forget the effects on family and friends or how we can educate them to help in an appropriate manner. It can also be difficult for significant others to accept the person close to them has a mental illness and/or they may feel powerless to help (Wilkinson and McAndrew, 2008).
7.2.3 - SEEKING TREATMENT

Stephen was diagnosed with an ED at the age of 14. He wrote that he was diagnosed with “anorexia” (Stephen Line 10), however later he was told “because my BMI wasn’t below a certain level I didn’t fit the criteria for anorexia. When actually two of the needed criteria were only possible for women” (Stephen Lines 245-47). This would indicate that his initial diagnosis was that of EDNOS, as his BMI was not low enough, therefore his weight had not dropped far enough to be labelled anorexic. Within this interview Stephen made reference to his anorexia, perhaps choosing to do this rather than referring to him having an EDNOS as there may be greater recognition of the former as opposed to the latter.

Again, the issue of using BMI for diagnosis is concerning. It is not clear from the transcript if an association was made between Stephen’s diagnosis and delayed puberty by the medical profession. For women, amenorrhea (a sign of delayed puberty) would have been included in the assessment of a female thought to have anorexia. However, for men, a gender not strongly associated with anorexia in society, delayed puberty might not have been readily considered. Stephen’s delayed puberty, whilst not fulfilling the criteria for anorexia, could also be considered an illustration of why DSM IV (2000) criteria needed to change.

7.2.3.1 - Treatment

Stephen’s treatment was solely within the NHS. He was treated with CBT, which lasted between one and two years, after having waited approximately ten months for an appointment. When asked if he was satisfied with his treatment he responded, “it was difficult to access, especially as I got older which for some could cause issues. Also, the waiting is so long that some people would probably give up” (Stephen Lines 180-81). When asked to clarify his comment, he responded by saying that whilst the area he lived in had specific child services, there did not seem to be the same level of services for adults. However, Stephen felt that his CBT had been “helpful but only as I wanted to recover” (Stephen Line 42-43). Initially Stephen’s motivation to recover was because “they told me that if I didn’t get better I would have had to of [sic] gone in hospital which is what was my main drive as I didn’t want to go into hospital” (Stephen Lines 19-20). It is not clear who told him this, but being admitted to a psychiatric hospital could be frightening to a 14-
year-old, especially one who perhaps relied on his control of food to have a sense of control over his life (Button and Warren, 2001).

As well as CBT, group therapy was offered to Stephen. After trying it Stephen then refused to go as he “was always the only male there” (Stephen Line 182). This, Stephen felt, marginalised him, and he believed that male only groups would be better. Whilst this has been highlighted in the literature (Weltzin et al., 2012), this could be rendered impractical, as men with eating disorders among hospital populations are relatively small in comparison to women. Stephen also stated that he “find[s] it difficult to talk in groups” (Stephen Line 254-55) which is not surprising given his history of isolating himself, and this may have also contributed to his poor experience of group therapy. Stephen’s refusal to engage in group therapy may also show his lack of esteem, as regardless of being the only man in a group of females, they all had something in common, and it could have been an opportunity to build relationships even on a superficial level. However, being the only male in the group, it could also have been a threat to his masculinity.

7.2.4 - MASCULINITY

Stephen felt that his masculinity was affected by his ED. Interestingly, he wrote that he had not “got the stereotypical manly bulked up body” (Stephen Line 73), which may indicate that whilst he may have not actively thought about “male role models” (Stephen Line 77), they appear evident in his pre-conscious. Stephen wrote that his ED has affected his voice and that he is; “often mistaken for a girl on the phone and it really upsets me which has led to me not being able to speak on the phone” (Stephen Lines 74-75). Presumably, this is why, as discussed previously, the interview was conducted via email; this had an emasculating effect for Stephen, which is identified and discussed further in Section 7.2.5 about relationships.

Stephen wrote that his father’s reaction to his ED was not helpful, with Stephen feeling that this was because of his father’s traditional masculinity (a man is a man). When asked to comment on this Stephen wrote; “I feel it is very old school and is now slowly opening to more variation rather than it being typical stereotypes like a man must like football etc” (Stephen Lines 221-223). The reference to football and sport was interesting and a
recurring theme amongst the participants’ narratives, whereby sport is almost the modern equivalent of the medieval martial arts of knights in their code of chivalry.

Interestingly, Stephen’s narrative also indicated the role of social capital in his upbringing. Stephen stated that he did not want people’s pity (specifically in employment which is covered in Section 7.2.6). When asked where he felt this thought came from, he responded; “I feel it's from my family, we have always been of the mind set of we don’t want pity we just solider on” (Stephen Lines 236-37). The preceding quote does show quite a traditional view of family, and it can also be interpreted as being stereotypically masculine. However, the problem with this is that Stephen talks about his family’s attitude as a whole being stoic, so rather than being gender specific i.e. strong males, emotional females, there is a level of social conditioning and social roles which cross the stereotypical boundaries.

7.2.5 - EFFECTS OF ANOREXIA ON LIBIDO/RELATIONSHIPS

Stephen wrote that whilst he is heterosexual he had not had a “proper relationship” (Stephen Line 46). This, he believed, was due to his ED experiences and delayed puberty, as he had “no self-confidence and self-worth” (Stephen Lines 46-47), and his voice had never broken properly, which “causes issues when meeting girls” (Stephen Line 48). What Stephen meant as a “proper relationship” is open to conjecture, however in line with other interviews and academic research (Fichter and Daser; 1987; Freeman 2005; Lindblad, et al., 2006; Agalusca et al., 2012) it could be assumed he is referring to sexual relations. Stephen felt that his low self-confidence around relationships was a combination of self and how people react to him, although he added that he felt it was mostly due to feelings about himself. Self-loathing is often a mindset and is typical amongst people with EDs (Treasure 2005), and one, such as in Stephen’s case, that leads to withdrawal and isolation.

7.2.6 - EMPLOYMENT

Within his narrative Stephen suggested his energy levels affect his working ability during his employment. Although he did not give any specific examples, it is clear that the effects of his ED have been long lasting; his behaviour started at 14 and he stated that he was a graduate in his pre-interview questionnaire. This meant that in terms of full time
employment it is most likely that he started this in his early 20s, and he spoke of his low energy levels impacting on his ability to work. The fact that he has disclosed his disorder at work can be interpreted that he still suffers from ED behaviour or its effects.

He also stated that his ED had lowered his confidence during work. He wrote that most of his employers know about his eating disorder; this is perhaps because he has felt the need to explain to them about the problems he has with his voice. However, Stephen did not want to be treated differently or for them to “pity me” (Stephen Line 61). The use of the term “pity” can be interpreted in many ways. When asked why he used this particular phrase he responded “because that’s one thing I don’t like, so I feel that if I don’t tell them then there is no chance of them giving it to me” (Stephen Lines 143-44). Perhaps Stephen has had negative experiences that stem from people’s reactions, not being of anger or humiliation; but by giving too much sympathy or by drawing attention to his ED with his colleagues. This can be emasculating if he is being treated differently. It is perhaps surprising that for the first four years of his ED only his family knew, but he now feels a need to inform his employers. Alternatively, he could have disclosed when filling his pre-employment health questionnaires, although this would not be in keeping with him wanting his ED to be confidential. In Stephen’s original answer about his employment he wrote; “most of my employers know about what I have been through” (Stephen Line 60). However, in line 144 (quoted in the previous paragraph) he indicated that he did not want pity and therefore did not want to tell employers. This creates a dichotomy for Stephen of how he explains his health status when asked.

7.2.7 - STEPHEN’S OPINIONS OF ED PORTRAYALS

Stephen thought that the portrayals of men with EDs was “pretty much non-existent” (Stephen Line 64). When he had seen examples they were of super skinny men or super bulked up men, in short sensationalist narratives/stories. In terms of what should be portrayed, Stephen thought that there should be a focus on honesty to show that being ill is not weak and that it is not unmanly to admit to a problem. He also believed that shock value, in terms of how it is reported, stories and photos of bodies, are not helpful and should be stopped.
Stephen knew of, and had volunteered for, both Beat and MENGET. He was asked how he felt about the role of the charities to which he responded; “I feel it’s a job that is so important to help and educate people” (Stephen Line 151). Interestingly and continuing on this theme he stated that low awareness of eating disorders was due to the media’s lack of interest in the subject and not the charities’ work.

**7.2.8 - KEY POINTS FROM STEPHEN’S STORY**

- **Personal and Background**
  - Mental illness and weight issues at home.
  - Bullied at school for his appearance.
  - Isolated socially with no proper relationships.
  - Delayed puberty.
  - Poor reaction to ED from his father.

- **ED Manifestation**
  - Food restriction.

- **Educational Experiences**
  - Did not get much help at school and felt his gender was an issue. Did get counselling which removed him from class at various times.

- **Treatment Experiences**
  - Originally not diagnosed as fully anorexic – yet had delayed puberty.
  - Waited ten months for a CBT appointment.
  - Felt marginalised being the only male in group therapy.

- **Work Experiences**
  - Issues due to low energy.
  - Did not want to tell employers about his ED, because he did not want to receive pity.

- **ED Portrayals and ED Charities**
  - Felt male portrayals non-existent, but felt this was not the fault of charities.
  - Felt the charities were doing good work.
7.2.9 - THE ENIGMA SUMMING STEPHEN UP

There were so many questions unanswered from Stephen’s interview and the stop/start nature of it highlighted some of the issues of an email interview. However, what was apparent was Stephen’s isolation and lack of confidence, in part due to being bullied and also because of his anorexia, whereby the effects of his delayed puberty still affect him in his twenties. Whilst Stephen underwent therapy and it seemed his weight and eating were under control, the psychological problems he identified are still in existence.
CHAPTER 8 - KEVIN’S STORY

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons
8.1 – OVERVIEW

Kevin was interviewed twice, on both occasions over the phone. The recording of his first interview, due to a number of audio issues, was unable to be transcribed properly to provide full context to his answers. Kevin was asked if was would be willing to redo the interview which he was. In the debriefing period after the first interview he made some comments which he thought may be helpful and asked for them to be on the record. He was informed that anything from within the debriefing period could not be used, but if he wished for additional information to be considered he would need to send this in an email. Kevin duly did this and his comments from this email are referenced in this analysis, as well as from his second interview transcript.

8.2 – BACKGROUND

At the time of his interviews Kevin was approaching his mid-thirties. He classified himself as bi-sexual, but had not had a romantic relationship since 2010. He reported a history of disordered eating behaviours and self-harm at various points in his life, spanning close to two decades in time. His current bout of ED behaviours had started after his last relationship had ended. Kevin by profession was a civil servant with middle/senior level managerial responsibilities and had taken unpaid leave in order to get treatment. At the time of the interview he was in discussions with his employer about being allowed to take sick leave as his treatment was taking longer than expected. Kevin was not asked about his treatment experiences as he was still undergoing treatment.

8.2.1 - FAMILY

Kevin identified his background as white middle class. He had a brother, but it was not ascertained who was the eldest and youngest. Kevin’s parents were still together. He said of his family relationships growing up; “I had a stable, relatively happy early childhood. My parents are both still together; I had a reasonable relationship with them and with my brother.” (Kevin Lines 124-26). Kevin’s use of the word “reasonable” was interesting and provocative when describing his relationship with his parents. When later in the interview
he spoke of role models he said of his father; “I have always felt closer to him and had a much better relationship with him than I have my mother.” (Kevin Lines 213-14).

Kevin added that there was no history of mental illness in his family, but he also said that he would not be surprised if his father had suffered from undiagnosed depression. He also felt that there were no weight concerns within his family. However, the first exposure to EDs was in his first relationship aged around 16; his girlfriend had suffered from anorexia before their relationship began. It may be a coincidence that his own ED behaviours began at this time in his life. It must also be introduced at this juncture that Kevin spoke of his weight, pre his most recent ED episode, to be around 100kgs which equated to a BMI in the higher echelons of the overweight category.

8.2.2 - EDUCATION

Kevin is well qualified, holding a post-graduate degree and having experience on graduate training schemes. Unlike many of the men interviewed who had university experience, Kevin was positive about this saying; “it was one of the happier times of my life when I was at university” (Kevin Lines 246-47). It would appear at university Kevin experienced somewhat of a sexual awakening, as he “came out” (Kevin Line 159) as bisexual, and he also became active within the university’s LGBT society, actively studying feminist theory and history. At this point Kevin was openly questioning his masculinity (discussed in Section 8.6). Taking a step back from his university experiences, Kevin thought his experiences of school could have been an influencing factor in his low opinions of himself. He said “I was bullied at school and that, I think, can have impacted, it was a stimulus to behaviour when I was a teenager” (Kevin Lines 128-30).

8.2.3 - BULLYING: A POSSIBLE SOURCE FOR KEVIN’S PROBLEMS

The cause of Kevin’s bullying was not shared and any reasons would be speculation. However, Kevin admitted to not enjoying contact sports. His future life indicates that he may have been a high achiever and he also described his personal self-image as “fat and weak” (Kevin Line 483). These factors could easily be reasons for him being bullied. However, the reasons for the bullying may not be important, as Kevin has developed defence strategies that have continued to protect him for much longer than his school days.
In order to deflect the bullying at school, Kevin employed a form of emotional repression; “it was one of the ways to avoid attracting attention at school when I was being bullied” (Kevin Lines 376-77). By not reacting to the bullying, he would stop the bullies getting enjoyment from his reactions, and therefore protect himself. He said “I deliberately cultivated this image of myself to be quite cold and quite cynical, that’s partly me and partly the mask that I put on to hide what was going on underneath.” (Kevin Lines 378-80). However, the mask that he created to hide emotions at school appears to have become much more attached to him than he would wish in adult life, as he struggles to show his emotions.

8.2.4 - BULLIED, TEENAGE AND EMBARKING ON SELF-HARM

When Kevin shared that he had been bullied at school, he said he thought that it was a stimulus to his behaviour as a teenager. This behaviour he spoke of was cutting, and a number of his friends at that time shared the behaviour. Kevin said “we never really talked about it, but it was something there. If I was thinking back, it’s probably, I wouldn’t say it put the idea in my head, but it probably normalised it slightly.” (Kevin Lines 233-35). This normalisation of self-harming behaviour is important, in the interests of fairness, as to the effects of bullying. Kevin may have started cutting because of the bullying and his low esteem, but he may have continued because it may have given him a sense of belonging within a peer group (Copes and Williams, 2007). Likewise, his cutting could also be a way of coping with the stress of being bullied (McAndrew and Warne, 2014). Or it can be offered as an example of fitting in with his friends at that time, an example of Connell and Messerschmidt’s (2005) expansion of hegemonic groups to local levels. This could still be argued within peer groups which were of mixed gender. Kevin’s self-harming behaviour did not start and end with cutting, as in his teenage years he started various forms of binging and purging behaviours, sometimes together, sometimes independently. This continued intermediately into his twenties, with Kevin describing such binges as;

A binge to me, when it was at its worse as a bulimic kind of thing would be several tubs of ice cream plus half a shelf of cakes or cream cakes and stuff. I could easily go through £20 or £30 of food in one go (Kevin Lines 97-102).
8.2.5 - THE DRIVE WHICH PUSHES KEVIN

A common trait associated with people with anorexia is that of being driven or high achievement. In some ways Kevin appeared quite guarded about his past and only shared some basic facts about his early years and time at university. However, it could be assumed academically he must have been a high achiever as he held a post-graduate degree. He had also been selected for graduate training schemes which are often competitive, with academic requirements being high to be selected just for an interview on such schemes.

Whilst Kevin did not specifically say what his job was, he did say that he had management responsibility directly and indirectly for around fifteen staff, indicating that he was at least a mid-level manager. He also spoke of a security clearance and on his demographic questionnaire identified working in the civil service. What can be interpreted with some assurance is that Kevin’s position was one of responsibility and was likely to have required good academic achievements, drive and ambition.

A further example of Kevin’s drive, ability to focus and, in a way take control of his life, is his vegetarianism. Kevin became a vegetarian at the age of 21 whilst at university. He stated that he made the decision when not in the thralls of an ED and during one of his happier times of his life. Kevin’s vegetarianism has raised questions within his treatment and he stated; “I have had long involved discussions with my dietician about if my vegetarianism was just a cover for my eating disorder or am I actually a veggie.” (Kevin, Lines 243-44). In Kevin’s mind, his vegetarianism and ED were totally separate and not a form of covert restriction as suggested in discussions with his dietician. However, Kevin did state that he believed his vegetarianism does, and did, make food restriction easier, as many foods were not allowed. He gave a specific example of when buying sandwiches for his dinner; his only option from the retailer was one vegetarian low-calorie sandwich. However, this suggested he only used one retailer, thus perhaps unconsciously restricting his options further. Another reason why Kevin believed vegetarianism made food restriction easier was because it “probably actively channelled me into following those rules type behaviour,” (Kevin Lines 250-51) meaning that he was more conditioned and better able to cut foods from his diet.
8.3 – KEVIN’S ED MANIFESTATION

Kevin’s ED (binge and purge) behaviours were intermittent, coming and going at various points in his life. However, he identified that in 2010 his behaviours stayed and food restriction started. In addition to food restriction, he also exercised, running between 30-40km a week, reflecting; “I ran not an excessive amount, if you were training for a marathon, but an excessive amount if you are trying to eat 1200 calories a day” (Kevin Lines 108-110). His binging and purging also got out of control, to the point where he was binging and purging 10-15 times a day and weighing himself two to three times daily. This was the catalyst for him to seek help, but it had taken two and half to three years of these behaviours for him to do so. Kevin felt that his most recent bout of ED behaviour was an attempt for; “counter-acting things, the stress of work, depression.” (Kevin Line 111-112). However, while not verbalised by Kevin, his last romantic relationship ended in 2010 (Kevin Line 285), and this might have impacted on his deterioration in terms of his ED.

8.3.1 - THE GOAL

According to Kevin, the goal of his ED “wasn’t so much about trying to get thin” (Kevin Line 481-82). He continued “I have never been muscly and never tried to be muscly …having said that, always, sort of, part of my self-image of me was fat and weak, it was about being skinny” (Kevin Lines 482-83). As a bisexual man, Kevin’s opinion was interesting; research suggests that gay men tend to try to be thinner, whilst straight men want to increase muscle (Cooperman, 2000; Núñez-Navarro et al., 2012). Although Kevin was not homosexual, his drive for thinness was much more in line with gay men. This could be for a number of reasons, one being that when describing his masculinity Kevin said that he “celebrated not conforming to butch male stereotypes” (Kevin Lines 155-56) and it may account for his desire to study feminist theory.

8.3.2 - FACING THE PROBLEM...ALONE

For many of the men interviewed, the influence of loved ones had been a motivating factor to seek help and overcome the ED. Kevin seemed not to fall into this category. Whether this is because of isolation, the mask he wears, or it simply did not come out in the interview. Kevin did state; “It was my choice to go to the GP, there was nobody telling me
to go” (Kevin Line 56). Nobody telling Kevin to go to the doctors paints an evocative picture of his life; many of the other men had people close to them showing concern. In Kevin’s case this appears to have been absent regardless of his weight loss and changes in his behaviour being apparent. It is strange that not one of his friends, family or work colleagues asked or made suggestions about his health, perhaps reinforcing his isolation. By Kevin’s own admission he did not want people to know about his ED; “I just thought that it is a massive sign of weakness, this is something I should be able to cope with myself and without help” (Kevin Lines 365-66). Kevin also curtailed his social life and at work tried to put on an act. Kevin appeared to keep his private life private, as he was full of shame for having a “female illness”. When Kevin did tell people, he found they were aware he had problems and he was disappointed they had not said anything (8.5.2); perhaps they were scared to say something. One question which stemmed from this was his relationship with his family, as it took approximately four years from beginning restriction to telling them.

8.4 – REACHING OUT FOR MEDICAL HELP

I knew I had an eating disorder... I sort of knew that partly through the weight loss and partly through I had got to the point where I was weighing myself several times a day and restricting my calories I was eating. So, it was pretty clear to the rational part of my brain that I knew I was not well (Kevin Lines 49-55).

With these sentiments, and after approximately two and a half years of food restriction, Kevin sought out medical help by going to his GP. Kevin felt that his GP at first “looked a bit non-plus” (Kevin Line 50) at his disclosure. His doctor’s next reaction was to give him a test for depression and to then refer him to a community mental health team, who subsequently referred him to a specialist ED service. From the outside it seems strange that a person goes to their doctor describing an ED and is firstly tested for depression, and then referred to a generic community mental health team, rather than being referred directly to the ED service. While this may have been standard procedure within this particular NHS trust, some academics have highlighted that men struggle to access treatment at times, because GPs do not necessarily recognise EDs in men (Paterson, 2004; Soban, 2006; Brown, 2007). For Kevin, from first going to see his doctor to being diagnosed by an ED service took approximately three to four months.
8.4.1 - WHERE DO I PEE?

During some episodes of treatment, Kevin said he was the only male patient and at times this was difficult for practical reasons. “Being the only bloke can be difficult, stupid things like there isn’t a male patient toilet, I had to use the disabled toilet, so I am abnormal that way!” (Kevin Lines 450-52). When Kevin reflected upon this he added; “but on the other hand it’s a good corrective for 2000 years of patriarchy, so I can’t complain that much” (Kevin Lines 452-53), perhaps indicating a touch of humour, or it could potentially illustrate how he views himself as a second-class citizen and not worthy of being equal. This indifference to Kevin’s gender was further exemplified when he disclosed that he had asked to have copies of paper work sent between practitioners. Kevin received standard letters from the ED unit sent to his GP in which Kevin was described as ‘she’ (Kevin additional email 16th April 2015). Perhaps a harmless mistake, but for a man in Kevin’s position perhaps it is further evidence of him suffering from a female illness.

8.5 – SHAME, AVOIDANCE, AWARENESS AND A LITTLE ANGER – REACTIONS TO KEVIN’S ED

The reactions that Kevin had to his ED were on the whole positive, with perhaps the most negative ones being his own.

8.5.1 - KEVIN’S REACTION

Shame, because I…, yes, shame was the big thing; I see it as a big sign of weakness that I am suffering from depression and suffering from an eating disorder and I didn’t think anyone would understand. I still blame myself for having it, there is still a part of me that says ‘you knew’ (Kevin Lines 355-58).

Whilst Kevin identified that his behaviour escalated in 2010, it took him until 2013 to seek help. But in 2011, Kevin said, he was fully aware of what he was doing. Kevin’s shame is understandable, however it shows the power of emotion, as within Kevin’s group of friends in the LGBT community he stated that a number of them had suffered mental health problems, yet he still felt the stigma of his illness.

Kevin said that he struggled to keep the ED to himself and, on a professional level, he must have had serious reservations about his future career in the civil service and
disclosing. On a personal level, he only told his best friend two months after being diagnosed, his other friends twelve months after diagnosis and his family eighteen months after his first treatment. This reluctance to share or even trust those in his personal life with his ED is perhaps an example of the stigma many authors have reported (Weltzin et al., 2005). Kevin also spoke of a mask (coping strategy) he wore behind which he tried to hide all emotion. Kevin believed this had evolved from being bullied during his school days, which is consistent with Ramirez (2013) who identified masking being used by victims of school bullying. Kevin’s desire to keep his ED private brings into question his relationships, particularly with his family, who he did not confide in until 18 months after his first treatment. This could indicate a lack of closeness or perhaps Kevin did not want to “burden them” with his problem.

Refusing to show others his “weakness”, in Kevin’s case his ED, is a trait often ascribed to masculinity (Connell, 1995). However, this is gender stereotyping evident in society. Rightly or wrongly however, with social conditioning, it is conceivable that Kevin may have consciously or unconsciously not wanted to feel more emasculated than he already felt. On this note Kevin said that he cared deeply about what his friends thought of him, admitting he probably cared too much. He stated; “I just thought that it is a massive sign of weakness. This is something I should be able to cope with myself and without help” (Kevin Lines 361-66). When Kevin did tell his friends, he was surprised at their reaction, especially as he had tried to hide it.

8.5.2 - FRIENDS’ REACTIONS

It took Kevin around twelve months to inform most of his friends about his ED and when he did he was surprised by their general reactions saying; “lots of people said ‘yes we were worried about you as you was clearly losing weight, and was clearly very stressed and was quite depressed’, but nobody said that was a surprise” (Kevin Lines 300-302). This was off-putting and Kevin’s next comment perhaps shows the self-absorption of the illness; “I thought it was bloody obvious that I was struggling, nobody was, If they were, reaching out for me, I didn’t notice and that made me feel like people didn’t care, ‘oh you’re not ill enough’” (Kevin Lines 303-06). This demonstrates ambivalence on Kevin’s part, he did not want people to know, but then he was disappointed when his friends did not say...
anything. In many ways, it was a no-win situation for them, as one can imagine them getting short shrift if broaching the subject, yet their lack of concern was also disappointing. Furthermore, Kevin’s comment that he felt because people had not said anything they were making judgements about the severity of his illness. This perhaps goes some way to show how rational judgement can be impaired when negativity takes over, and how this can impact on people’s self-worth.

Of his friends, Kevin felt that only one of them drifted away. Initially Kevin said that this was understandable as his friend had just started a new relationship, but then said that he had heard it was; “partly because it’s something she doesn’t know how to deal with” (Kevin Lines 307-10). It could be suggested from this statement that he was making excuses for her behaviour because he felt other people’s feelings were more important than his own (Treasure, 2005). In hindsight, Kevin reflected that his concern his friends would not stick by him or understand his ED was not necessary. They had been his friends for a long time and, in that time, he had suffered bouts of depression and had been experiencing his ED for a long time before he told them, so if they were going to desert him on mass they would have done it long before he told them.

8.5.3 - WORK - COLLEAGUES

It appeared that Kevin kept most of his work relationships formal, as many of the people he came into daily contact were subordinates. He also stated; “I probably am more straight acting at work than anywhere else” (Kevin Line176-77), highlighting how, as humans, we act differently in different situations, akin to dramaturgy (Goffman, 1978) an offshoot of role theory.

Kevin told his immediate manager at work at around the same time he told his best friend, however it was around twelve months and after a sickness break (because of his illness) that his team found out. Kevin felt people were on the whole “brilliant” (Kevin Line 421), although one female got very angry, but he; “never really explored with her whether she was angry with me because I had taken the time off or because I had let myself get into such a state” (Kevin Lines 315-17).
8.5.4 - WORK/CORPORATE

Whilst the reaction from Kevin’s colleagues and immediate managers, with one exception was very good, the corporate reaction was questionable to say the least. Telling his manager meant that his employer, the government, had formal involvement. This involved him having to, and continuing to have to, declare all his interactions with health services. Kevin was sent, after initially disclosing his ED, to see occupational health, who furnished a report to his managers which Kevin described as containing; “pretty graphic detail” (Kevin Line 431). The result of the report indicated Kevin should have his responsibilities increased. This recommendation appears at conflict with him experiencing an ED. Kevin said; “they chose to almost immediately double my responsibility which was not just doubling my team, but taking on some quite difficult management” (Kevin Lines 432-33). This reaction was totally baffling, giving a person with health difficulties more responsibility is at best misguided and at worse could be seen as an attempt to get him to leave his position. The outcome for Kevin was that the increased responsibility; “was what helped push me over the edge” (Kevin Line 434). Pushed over the edge is emotive terminology and in Kevin’s case his edge was described when he said; “I had to take a couple of weeks off work last summer because it got to the point where I was scared that if I went into a xxxx station I’d throw myself under a train, which wasn’t a whole bunch of fun” (Kevin Lines 310-13).

Kevin had to engage in day care treatment spending all weekdays within an ED unit, going home at night and during the weekend. This resulted in him having to take unpaid leave. Kevin’s recovery did not go as quickly as he expected/hoped and whilst in treatment he approached his employer about going onto paid sick leave. He felt that the HR department was not the most helpful saying, that they were easier to deal with when he had to take unpaid leave as opposed to trying to go back to work. He stated that “the response I got back from HR was essentially they can’t find any reason in their policy, why they can’t find a solution, [for him to go back to work] rather than what is best for me and best for the department” (Kevin Lines 226-28). Whatever the implicit message, Kevin’s framing of it was from a negative stance. He found the response to his request puzzling, as it appeared to him that rather than finding a way to help him return to work (positive message
framing), their response was that they could not find a way to prevent him returning to work (negative message framing).

8.5.5 - THE FAMILY’S REACTION

Kevin’s attitude towards his family, as with any interpretation, can be viewed in a number of ways. Kevin did not tell his family until approximately eighteen months after having been diagnosed. They were the last group he informed and it would appear from his narrative that this was after taking time away from his job because of his self-harming fears. This course of inaction could be the result of a poor relationship with his family or it could be Kevin’s way of protecting them. Kevin’s transcript provided substance to both scenarios. Kevin said that his brother was easy going and his reaction was positive.

Kevin’s parents’ reaction was quite different. Kevin told his parents about his ED over the phone, which is quite surprising given the length of time which had elapsed between his diagnosis and the conversation. Kevin may have made a spur of the moment decision to tell them or he may have been worried about their reaction and any shows of emotion which he would have had to face. Of their reaction Kevin said; “I think there was a certain amount of relief I was admitting I had a problem, because it was certainly clear to them that something was wrong as I was so thin, and I had been very stressed with work” (Kevin Lines 333-36). This would indicate that Kevin did have a relationship with his parents, whereby he did see them with some regularity, as they had seen that he had lost weight and he must have confided some of his work-related problems. Kevin said that their initial reaction was to; “blame my job” (Kevin Lines 339-40), with his dad asking what Kevin felt was the cause of the ED and his mother stating it had nothing to do with them. His mother’s reaction can be interpreted as being defensive, not wanting his illness being attributed to his upbringing (Crisp et al., 2001). This not being a particularly helpful reaction was further emphasised by Kevin’s comment; “we haven’t really spoken about it that much” (Kevin Lines 341-42). Of this conversation with his parents Kevin disclosed that he felt; “it helped them, when I told them, I already knew I was well on the path of getting the treatment” (Kevin Lines 336-37). This may answer the question as to why it took him so long to tell his family about his ED because he felt on the way to recovery; however, it could be a way of Kevin justifying his decision not to tell them.
8.6 – BEING A MAN KEVIN STYLE

8.6.1 - MIXED UP MASCULINITY, LOOKING FOR A PLACE TO FIT IN?

Kevin’s masculinity or, from his perspective, a lack of it, has played a prominent role in his life. At university, after disclosing his bisexuality, and as an active member of the university LGBT movement, Kevin “thought about gender and queer theory quite a bit” (Kevin Line 143). He also studied feminist history, which would indicate a search for meaning or his fitting within a specific social stratum. Kevin said; “I probably do over analyse my relationship with masculinity” (Kevin Line 144). Kevin’s bisexuality cannot be ignored as he may not fit into one community or another. Being sexually active with men disqualifies him from hegemonic masculinity in straight society, and within the gay male community it would put him perhaps outside the dominant masculinity, especially as he is not actively involved within the hierarchical roles within the gay community.

Kevin’s lack of belonging is illustrated in his desire, on the surface, to reject what he believes is masculinity, whilst in reality he acknowledges that there is a part of him which wants to be seen as masculine. “I sort of both celebrate the fact that I don’t conform with being a stereotypical butch stereotype. But on the other hand, I do also know that deep down there is a part of me that wishes I could pass” (Kevin Lines 155-57). Whilst “living a lie” may be too strong a term, it does serve to illustrate Kevin’s plight and highlight a lack of comfort in his skin and a desire to try too hard and be all things to all men. Kevin believes his friends would describe him as camp, yet when he disclosed his bisexuality one of his friends said; “bloody hell you’re the straightest boy I know!” (Kevin Lines 159-60).

Perhaps Kevin’s ‘campness’ has been allowed more freedom to grow since he came out. It could be argued a friend who uses the term ‘boy’ about someone who was eighteen or nineteen may not be the best judge of stereotypical masculinity. However, this may indicate that within Kevin’s friendship groups he may receive mixed messages as to how people saw him. Added to this is his behaviour at work, of which he said; “I probably am more straight acting at work than anywhere else,” (Kevin Lines176-77) and a picture builds up of many different masks being worn. This statement suggested his camp behaviour is moderated at work, perhaps indicating a belief that to succeed in his career and lead people he needed to be more masculine. Kevin also stated he is not totally...
isolated, but he does find interacting with people difficult and is introverted, characteristics that would seem to be at odds with someone who describes himself as camp. Wearing so many masks for his different roles and, for example being, ‘camp’ with his friends and ‘straight’ at work, one must ask if Kevin actually knows who he is.

8.6.2 - MASCULINITY - FORGED ON TO THE SPORTING BATTLE FIELD

“I have never been a particularly masculine man,” (Kevin Line 148) Kevin stated before continuing; “I didn’t really play contact sport at school, and I am not particularly sporty. I like musical theatre” (Kevin Lines 148-49). The allusion, as with many of the men interviewed, to masculinity and sport, is both revealing and disturbing. As is his belief that having a liking for musical theatre is emasculating. This is revealing because Kevin has demonstrated educational attainment and aptitude within his career to lead and more importantly be followed, yet he sets his masculinity standard to a level of physical prowess on a sports field from his youth.

He did say that he did take part in aerobic sports at school, namely running and swimming, both individual sports, and badminton. All three are highly competitive with the first two as well as being played against people, also measured against the clock; although he may not have seen them as being masculine because they are not decided by physical contact.

For all Kevin’s reading on feminist theory he seems firmly rooted in a stereotypical view of masculinity when it comes to his self-perception, attributing his enjoyment of the theatre and his willingness to reflect upon his emotions as emasculating.

Murnen and Smolak; (1997) and Meyer et al. (2001) indicate that femininity is a contributory factor in the likelihood of an ED; and it is not surprising that Kevin would consider many factors in his life to be feminine, such as the lack of sporting prowess, liking theatre, his leaning towards most of his closest friends being female and his comfort in their company as opposed to males. However, in contrast, Kevin was involved in a long-term relationship with a female from the age of sixteen

Although Kevin felt that in order to combat the bullying he received during school he; “deliberately cultivated this image of myself to be quite cold and quite cynical, that’s partly me and partly the mask that I put on to hide what was going on underneath” (Kevin

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Lines 378-80). One cannot help but wonder if this is the only reason for his lack of emotional skill. In his transcript Kevin’s observations about his own masculinity, and the reaction of his family to not talk very much about his ED, indicates a traditional stoic stiff upper lip approach. The problem for Kevin is, with no way to positively channel or release his emotions except for ‘unmanly crying’, he became a victim, knowing how he ‘should behave’, but unable to do so. Of his emotions Kevin said;

I’ve always tried not to show that on the outside. I have always struggled with emotions and towards other people; I am just really rubbish at dealing with it. I would just sort of burst into tears, that sort of thing (Kevin Lines 372-75).

A further deviation from traditional masculinity was evident when Kevin was asked about role models and who he looked up to growing up. Kevin’s assertion was that it would have been someone from a popular band, but not the leader, one of the people in the background.

8.7 – THE EFFECTS AND CHARACTERISTICS OF KEVIN’S ED

8.7.1 - BEING THE BEST

Perfectionism is a trait often associated with people with EDs and Kevin acknowledged; “I think I have a strong streak of perfectionism” (Kevin Line 193). Within his narrative there were examples of this trait. Although, as discussed previously, Kevin viewed his masculinity through contact sport, he is not a person who does not enjoy it. Kevin spoke of his liking for watching sport, however he added that he critically watched not in the immersion of a spectator, who rides the rollercoaster of emotions, but of the pundit whose job is to analyse weaknesses, suggest improvements and praise strengths, which indicates his perfectionist tendencies (Treasure, 2005). A further piece of evidence which can be attributed to perfectionism was when discussing the perceptions of anorexia. Kevin stated; “I know there is in some ways a perception that anorexia is in some ways more prevalent in LGBT men, I am not sure that is true or not I’ve not seen any stats on it” (Kevin Lines 491-93). The rider at the end of Kevin’s sentence shows a mind that needs to have the facts before making a decision, elements of perfectionism and control.
8.7.2 - HOW CAN I BE LIKED? SELF-CRITIQUE AND PEOPLE PLEASING

Low self-esteem and self-worth are traits common in people with anorexia, and these can be manifested in a desire to please people and put others in front of their own needs. This could be one reason why Kevin did not tell his parents about his illness as he did not want to make them unhappy, even though a rational person would have known that they could see his weight loss and may have had concerns over his health. Another aspect of this behaviour was shared by Kevin when he said that he works out what he is going to say before saying it and will then; “play the whole conversation back and pick apart what I say” (Kevin Line 198). The reason for this level of control and analysis of one’s words must relate to a fear that they will not be received well, considered or accepted by an audience. This is further compounded by Kevin’s feeling of; “having part of me constantly looking over my shoulder and criticising what I am doing” (Kevin Lines 193-94).

8.7.3 - BEING ALONE IN THE CROWD

“I felt I was quite isolated. I probably wasn’t as bad as quite a lot of people” (Kevin Lines 276-77). Kevin’s levels of isolation may not, as he points out, be as high as those typically associated with EDs. Kevin did acknowledge he has felt isolated, finds it difficult to interact with people on a social level and is introverted in nature. Kevin spoke about friendships amongst the people who, as a teenager, used to cut (self-harm) and also at university and up to the present day. This does point to him not being totally isolated. However, Kevin said; “at times the disorder made me quite antisocial and isolated” (Kevin Lines 288-89) and the physical effects, if not the mental ones, made him cut down, if not completely stop, the social aspects of his life. As a result of this, his energy was invested in his job and his free-time invested in the ED. His isolation would have been intensified by the periods where his libido/sexual drive had reduced/ceased, in part due to starvation syndrome. This would have allowed him to further isolate himself from others and think negatively. This can result in a vicious cycle, whereby isolation would compromise his ability to form relationships perhaps, through lack of confidence feeding his decreased libido, and lack of libido would in turn feed isolation.
Kevin noticed mental consequences which could be attributed to his ED. He noted that his behaviour was much more impulsive, he had bouts of anger and felt that he did not have the same levels of mental endurance that he once had. Kevin said that when he got hungry and stressed he could get; “quite nasty” (Kevin Line 401). Considering that his ED is based around food restriction, with hunger and stress being natural results from this, it could be interpreted that Kevin must have spent a lot of time being nasty or short with the people around him. Kevin potentially acknowledged this when he said; “I have been known to be very angry a lot more” (Kevin Line 402). Kevin’s anger is not always on show to others, as he stated that there are periods when angry with the world, but his emotions were internalised.

Kevin’s cognitive ability to function was also impaired, with him noting that his concentration span was; “completely blown” (Kevin Line 408), believing this was due to a lack of energy. Kevin said;

I was finding I could still perform at work and certainly when the pressure was on at work, I could still perform really well, but I was then going home and completely collapsing, whereas previously I would do a full day in the office and then go out with friends or whatever or go home and be able to read or watch TV (Kevin Lines 409-13).

Kevin’s ability to function at work was not surprising as it common for people with an ED to be able to channel energy into an element of life where they can continue to assess or push themselves (Engel et al., 2007). It was also no surprise, especially as Kevin stated he was trying keep his ED private. However, whilst Kevin said that he was able to perform well at work, he did also say earlier in the interview when giving an overview of his ED; “I was struggling to maintain the performance in my job” (Kevin Line 54) and it also needs reasserting that he had to take time away from work because of suicidal thoughts in part due to the stress of it. Kevin’s employment, his capacity and capability, are extremely interesting, especially with his employer’s response in giving him more responsibility and then their tardiness in terms of allowing him sick pay. But it is difficult, with the changes in his body and mood via his weight loss, how he would have continued to perform day in and day out to the same level as when fit and healthy.
8.8 – LOOKING AT ED PORTRAYALS

Kevin’s opening remarks on the portrayals of EDs in society and the media were; “I can’t think off the top of my head of ever seeing a fictional representation of a man with an eating disorder” (Kevin Lines 442-43). Kevin felt that the wider view of anorexia is; “it is an issue of teenage girls who’ve read too many copies of Heat magazines” (Kevin Lines 444-45). This, he believed, was not helpful as it is a label that does not fit many women, let alone men, and serves to help stigmatise and shame those who do not fit the stereotype. Kevin said; “I think it certainly made it harder for me. Feeling quite ashamed about having it and not wanting to talk about it. Part of that, maybe not consciously, but unconsciously was shame of being a thirty-year-old bloke with a teenage girls’ disease” (Kevin Lines 446-49).

 Whilst Kevin’s experience of ED portrayals was broadly negative, he was able to be more positive about an increase in mental health coverage in the media, citing the spin-doctor Alistair Campbell and a number of sportsmen who have spoken publicly about depression, as well as men with high powered jobs who are looked up to. However, his final comment on portrayals reverted back to EDs, which sadly summed up the thoughts of a number of the men interviewed; “What would have been helpful to me would have been able to see all types of men get eating disorders, different types of men get eating disorders and it’s not just the teenage girls” (Kevin Lines 457-60).

8.8.1 - HAVING TO FIND THE CHARITIES IS TOO LATE

Kevin said; “I am aware of Beat, I am aware of Men Get Eating Disorders Too. I’m aware via having to look for help, sort of googling things” (Kevin Lines 465-66). Whilst it was positive that he was able to find some help, the problem for Kevin was that he found the charities after trying to get treatment, whereas awareness of the charities or male EDs beforehand may have helped him to get treatment earlier or even deal with the ED better.

Of Beat Kevin felt that the target segment of the organisation is; “quite young and female” (Kevin Line 469) ... “most of what they put out is the story of Jane aged 19” (Kevin Lines 470-71). Kevin did not see this as a major failing of Beat, as he thought that the majority of people with EDs fall into this demographic. Whilst in some ways a fair opinion, it was
also quite surprising considering what he had experienced and how he felt that portrayals of people with EDs were too stereotypical. Perhaps it is another example of Kevin feeling that he was not as important as others (Treasure, 2005). Men Get Eating Disorders Too, whilst impressing him was in Kevin’s opinion too small. He stated that the charity was beginning to spread into his locality and that he would be able to try it out, but at the time of the interview he felt it was not “relevant” (Kevin Line 474), because of their size.

8.9 – TRAPPED IN A SHRINKING ROOM: LIFE WITH AN ED

The last question that Kevin was asked was ‘what is life with an ED like?’ He said; “Tiring, stressful, all consuming. You don’t have time to do anything else; it is all about the eating disorder and hiding it” (Kevin Lines 526-27). He went on to explain;

Anytime I have to day dream or whatever, and when you’ve got an eating disorder you have a lot, as you don’t have the energy and concentration to do anything else. I would be thinking about what I had just eaten or was going to eat that day or just how f*****d I was and then berating myself for being hungry. And that just gets knackering, so you can’t do anything else. (Kevin Lines 532-35).

These statements show how tiring and invasive the ED is within the mind. This tied in with a previous comment in his narrative in which he said; “the eating disorders and the restriction in particular becomes so all-consuming it’s an effective way of blocking everything else that’s sh*t in your life out” (Kevin Lines 112-14). The focus on the ED allows the person with it to ignore other problems and triggers in their life (Treasure, 2005).

To try and combat his ED one of the strategies Kevin has adopted is to try and become more open with people; “it’s f*****g hard trying to be as open as possible with a small group of friends about what is going on.... I have told people that, partly so they can support me if needed” (Kevin Lines 367-70). This change in his attitude will hopefully help, although the down side with the ‘black or white’ anorexic mentality is that he may go from not sharing at all, to too much, which may push people away. When talking about life with an ED it was suggested that it was like life in a bubble. To this Kevin replied with a comment which graphically sums up life with an ED; “Bubble is probably not a bad word;
my only problem with bubble is that a bubble is transparent. It’s more like being in a room with the walls or ceiling closing in on you” (Kevin Lines 532-38).

### 8.10 – KEY POINTS FROM KEVIN’S STORY

- **Personal and Background**
  - No history of mental ill health or weight problems in his family.
  - He was overweight as a child.
  - Bullied.
  - Isolated; formed relationships, but became distant especially during ED behaviour.
  - Bi-sexual, his first awareness of anorexia was due to the past history of a girlfriend (before his own ED behaviours).
  - History of cutting, binging and purging.
  - Wore a variety of masks, camp with friends, straight with work colleagues.

- **ED Manifestation**
  - Food restriction.
  - Exercise.
  - Vomiting.
  - Laxatives.

- **Educational Experiences**
  - High achiever.
  - Actively questioned masculinity and sought out feminist theory.

- **Reactions and Treatment Experiences**
  - Encountered sexual inequality during treatment.
  - Told his family 18 months after being diagnosed.

- **Work Experiences**
  - High achiever at work, civil service mid-level management.
  - Found that after he had sought help for his ED and told his employer, his employer increased his responsibilities and the number of staff under his supervision, despite them sending him to occupational health.
Consequently, had to take time off from work due to suicidal thoughts.
- Took unpaid leave for treatment.

- ED Portrayals and ED Charities
  - Only looked for charities once he was diagnosed, despite knowing for a long period of time about his behaviours.
  - Felt portrayals and charities focused on those young and female.
CHAPTER 9 - ALAN’S STORY

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons
9.1 – OVERVIEW

Alan was interviewed via the phone. At the time of the interview he was in his mid-20s, he was white, gay and experienced eating disordered behaviour from around the age of 15 into his early 20s, with the approximate duration of his illness being around seven years. Alan’s behaviour consisted of restriction, excessive exercise, laxative abuse and the taking of diet pills and amphetamines.

9.2 – ALAN’S BACKGROUND

9.2.1 - FAMILY

Alan’s family background highlighted a number of factors/events which could have contributed to his eating disorder. A number of these events happened in the year before his eating disordered behaviour began and will be presented in Section 9.2.2 of his narrative.

His narrative consists of mainly female role models, being in the form of his mother, whom he seemed close to, and his mother’s female friends. In terms of male role models Alan had never met his natural father. At the age of 11, Alan and his mother moved in with her partner, with whom he had never been close to. Indeed his description of this relationship gives some indication of his feelings towards him; “My step-dad (his name), I call him my step-dad but he’s just my mum’s boyfriend” (Alan Line 421-22). This was further exemplified by his step father’s reaction to his eating disorder (discussed in Section 9.3.11). Alan’s narrative alluded to his relationship with his mother being free from any paternal influences until she met his step-father. Perhaps after having his mother’s attention for so long Alan may have felt resentful towards anyone who was a perceived or otherwise threat to that relationship. Alan may have experienced insecurity with the change in his relationship with his mother. Within Alan’s narrative there was evidence of him having a closeness to his mother which may indicate a peer to peer, rather than parent to child relationship between him and his mother. Such relationships are common within single parent families (Martin, 2009). The arrival of his step father could have introduced multiple loses in Alan’s life; the relationship he had with his mother, his mother as a
friend, and her other friends, all of which would have added to his insecurity. However, at a more simplistic level his poor relationship with his step father may just be a consequence of them not getting along, or mutual dislike.

Alan had two half-brothers, one of them he had never met, the other he did not mention, save to say that he was born when Alan was approximately fifteen. In terms of his grandparents, Alan stated that he was close to them. Alan also stated that he grew up; “around my mum and family members dieting, usually quite unsuccessfully that way with their weight fluctuating” (Alan Line141-420), and therefore dieting and weight gain would have been normal patterns of behaviour for him growing up, initially making his own dieting behaviours justified.

9.2.2 - AGE 15

Around the age of fifteen a number of events happened in Alan’s life which may have provided triggers for his eating disordered behaviour which began around this age. Firstly, Alan experienced puberty and the body changes he experienced saw him get taller and thinner. Alan started to realise that he was gay, and at the age of fifteen he came out. Gender identity has been identified as a precursor to an ED (Bassett, 2002; Crisp et al., 2006; Lindblad et al., 2006). Regarding his sexuality at this point in time, Alan said he questioned; “how am I going to live a normal life? How I’m I going to tell people? I came out and it was a bit of a problem” (Alan Lines 594-596), uncertainties common among young homosexual people (McAndrew and Warne, 2012).

The second event that occurred was when Alan was informed, approximately a year before the manifestation of his ED, that his natural father had another child and he had a half-brother, whom at the time of interview he had never met. Thirdly, Alan’s mother had a child with her partner, which Alan described as being; “difficult for me” (Alan Line 74) as he had been an only child to that point and following the birth of his step brother he was no longer the sole maternal focus of his mother. Family stresses are often contributory factors for EDs (Tozzi et al., 2003) and as a result of these events Alan also decided to go on a diet.
9.2.3 - GROWING UP

As a younger child Alan described himself as being; “a chubby child not massively overweight, but I got the mick taken out of me a little bit, I was a bit podgy. I was quite unpopular and I looked smart and not very cool so that was always an issue” (Alan Line 62-65). This bullying led Alan to embark, with his mother, on his first diet during the time he went to high school. “The bullying was quite bad, so me and my mum we did the healthy thing and I did lose some weight in a very healthy way, very slowly. I did eventually put it back on” (Alan Line 144-146). The second time Alan began to diet to lose weight he found that he could not control his behaviour. Both childhood bullying (Copeland et al., 2015) and being overweight (Cooperman, 2000; Strober et al., 2001; Fernández-Aranda et al., 2004; Raevuori et al., 2008; Raevuori et al., 2009; Gueguen et al., 2012) have been found to be contributing factors to EDs.

9.2.4 - EDUCATION

Alan’s highest qualification to date were his A Levels; these results saw him take a place at university, where, away from his family background, he lost control. “I was very unwell I just wanted to get out [away from family] and be left to my own devices. But I think that [going to university] was possibly the worst thing that could have happened” (Alan Lines 366-368). Alan initially failed his second year at university, but eventually passed it. He found, with the effects of the ED, he was not able to complete the third year and he dropped out. His struggles at university may have been the result of cognitive impairment (from starvation) due to his illness, a factor often associated with EDs (Claes et al., 2012; Tchanturia et al., 2013).

Alan’s health deteriorated immediately after starting university. He found that with the academic pressures, and that of having to pay his bills and manage his flat, he became stressed. Prior to attending university his relationship with his mum had suffered and he had wanted to get away from home;

I didn’t have my mum on my back [on going to university]. She spent years trying to get me to eat and reminding me what’s healthy and trying to do the best thing for me. Without her there I was suddenly a lot happier, as we were constantly arguing. The anorexia side of me was a lot happier I could do what I want and get away with it (Alan Lines 396-400).
Added to this was Alan’s exposure to a gay community which, in his words, valued thinness and androgyny in younger men as sexually alluring (Brown and Keele 2012 and 2015). Perhaps with him losing control to his ED and its physical and psychological effects, his emergence as a sexual figure, and his views of his mother trying to get him to eat, all impacted on his ability to complete his studies.

9.3 – EATING DISORDER MANIFESTATION

When Alan decided to diet for a second time, around the age of fifteen, he; “learned about calories, I really understood fat, GDAs (Guideline Daily Amounts) and nutrition” (Alan Line 147-148). This statement could be indicative of perfectionist characteristics, often associated with people who experience eating disorders (Treasure 2005). Alan said that the introduction of an eating disorder into his life; “was quite insidious how it crept up” (Alan Line 148), although with family members dieting being a constant in his home life, it perhaps should not be that surprising. Alan suggested that he dieted normally and sensibly, however, after eliminating fats from his diet, the resultant speeding up of his weight loss was met with more extreme behaviours on his part; “the more weight I lost and then it kept spiralling out of control. It’s very addictive” (Alan Lines150-152). Worryingly, from the point of view of control, Alan said; “I couldn’t tell you the point when it got too much” (Alan Line 153), meaning that the point at which the illness takes over is not a clear event as Alan alluded to in Line 148.

Initially Alan’s behaviour revolved around food restriction with occasional purges via vomiting. Alan said vomiting was horrible, however he found it to be a release. When he purged in this way he felt a sense of release, stating it was also “quite nice” (Alan Line 763) in that he was able to master his body and his body’s natural desire not to vomit. Alan said he had similar feelings when using laxatives. By the time he reached university, and coincidently moved away from home, his behaviour began to change from restriction with some binging, to more binging and purging, with the addition of extreme exercise; “I was running in the gym for over 60 kilometres a week...I don’t know, I just got addicted to running all of a sudden” (Alan Lines 263-65). The running Alan was doing, 60kms (37 miles) a week, is 15 miles more than the subjects of the Minnesota Starvation Experiment (Keys et al., 1950) were asked to walk in their controlled experiment, which indicates his
level of intensity in his attempts to lose weight. Alan also used appetite suppressant/dieting drugs and laxatives to lose weight. At university he used amphetamines, both for recreational use and to suppress his appetite. His drug use led him to seek the help of a drugs counsellor, indicating the level of ‘distress’ in his life. However, on a positive note it was good that, firstly, he recognised he needed help and, secondly, that he actually received it. When asked about the many differing methods that Alan used in order to lose weight he said; “it was never all at once, it changed whatever I tried to do to stop it” (Alan Line 289). This indicated that whenever Alan seemed to find a way to control his weight loss, he would find a different way to carry on, at times these being more extreme; for example, going from reduced diet to slimming pills and harder drugs.

A major problem, and one which perhaps provided ongoing positive reinforcement to his eating disordered behaviour, was that for the first time in his life Alan started to receive positive feedback for his appearance; “I deemed it as praise from my family and people who had known me all those years, that was surprising in a nice way” (Alan Lines 156-158). When asked how this had made him feel he replied; “I suppose pride, I’d never felt before” (Alan Line 162). He also found that when he began to experience the ‘night life’ in the gay community his thinness made him sexually attractive;

   you go and drink and party, and you meet older men who are attracted to you and he thinks you’re the centre of the world and that’s what most gays get drawn into too; that’s why they fall into that image, that stereotype, young attractive and feminine (Alan Lines 657-660).

The whole change in his life, due to his weight loss, was summed up by Alan when he described the changes to his life; “suddenly becoming popular, people liking me, becoming more attractive, becoming more self-aware that became quite addictive; so that for me was part of it, what I assumed were contributing factors” (Alan Lines 68-70).

9.3.1 - EATING DISORDER GOAL

Alan believed that the driving factor in his eating disorder was his desire to be thin. This was broadly in line with other studies which have examined the goals of gay men (Williamson, 1999; Feldman and Meyer, 2007). Within the gay community that Alan was a part of at the time of his ED, there was a social hierarchy which he took part in and there
was a need for young gay men to aspire towards a “thin almost feminine kind of beauty” (Alan Lines 102-103).

as a young gay man, you’re kind of very sexualised into this kind of body image of being young, slim and clean shaven; it’s very pre-pubescent in a very strange way, a very Freudian way (Alan Lines 694-96).

Alan identified cultural stereotype as being a “TWINK”, and the more he adhered to this role the more he continued to be popular.

9.4 – REACTIONS TO ALAN’S ED

Alan’s narrative paints an interesting picture as to how people reacted to his eating disorder.

9.4.1 - FAMILY

Alan’s perception of his family’s reaction was; “My family were not supportive. At the time, I was horrified to their reaction. I can understand it now looking back” (Alan Lines 420-421). It appeared from Alan’s narrative his acknowledgement of his sexuality caused less distress. Alan talked about both his mother’s and step father’s reactions, finding a reason for his mother’s reaction, but not for his step fathers, which could indicate his feelings towards him. “My mum was angry and upset, but that’s just her; it takes her a while to digest things” (Alan Lines 421-422). Alan was accused of wasting food and money by his step-father, which resulted in a confrontation; “I didn’t understand it, I still don’t understand it, but it’s just emotions are screwed” (Alan Lines 441-442). Alan was not clear whose emotions he referred to. When asked how these reactions made him feel Alan replied; “I suppose it just added to the sense of shame, not just letting myself down, I was letting others down, that I just wasn’t worth it. The fact he brought money into it, it was wasting money and that was his biggest concern” (Alan Lines 451-453). Alan’s comments highlight the strain which can be put on families during illness and demonstrates how a lack of understanding, such as making (understandable) comments re the cost food of can be unhelpful (Treasure, 2005).
9.4.2 - FRIENDS

The reaction of Alan’s friends was the opposite of his parents. “My friends were full of concern and loyalty. It was just mainly my family’s reaction that was quite jarring and not nice” (Alan Lines 423-425). However, Alan’s friends at the time of coming out with his ED, and at the time of his interview, were mostly female. Alan’s explanation of their positive reaction was that they could relate to an ED easier than males, perhaps reflecting cultural stereotypes and pressures which exist in our society. Alan further added that whilst he did not have many gay friends, they understood EDs more than his straight male friends did.

9.5 – LIVING IN THE STICKS - ALAN’S TREATMENT EXPERIENCES

Alan’s first consultation with the medical profession was around the age of 15 and was instigated by his mother. Alan’s mother found out about his problems, second hand from one of her friends who he had confided in. An indication of the turmoil at the time of his illness coming to the fore was demonstrated in a comment Alan made; “mum wouldn’t come with me just as things were a bit rough” (Alan Line 239). However, Alan did not expand on this and it did not feel appropriate to explore it further during the interview. Alan’s mother, who may have had a negative reaction and difficulty controlling her feelings at the time, did manage, through a friend, to get him a one-off appointment with a leading private ED practitioner, which indicates a level of love and care. Alan’s initial experiences with the NHS were less than favourable, as his doctor would not prescribe anti-depressants because he was 15, yet did so as soon as he turned 16, three months after his first consultation. His doctor did refer him to a non-ED specialist counselling service within the surgery. Alan described his initial surgery-based counselling sessions as not being very helpful; “I went to a couple of those and didn’t find it very successful. I didn’t like the woman and they were a bit patronising” (Alan Lines 236-37). Alan’s next comment in the interview was interesting, in that he did not think the sessions were helpful because he lived at the time in “the middle of nowhere” (Alan Line 238) and he did not think the services were as good as they were in more urbanised areas. Instead of his GPs...
surgery sessions he engaged in the counselling services offered by his college, finding that he preferred these and stopped using the services offered by his local GP.

At some point Alan was placed onto a waiting list for specialist ED CBT. This wait was for two years and, given he stated that he finished his sessions around the age of twenty-one, it would appear that he was only referred for CBT around the age of 17-18. This therefore meant that when he initially presented to his GP aged fifteen, he had to wait a considerable period of time before being referred for CBT. This could indicate a number of issues; he may not have been deemed serious enough by his GP or by the specialist ED service to be put on the waiting list, or it could indicate a lack of specialist services in his area; or it could also be because of the number of people trying to access the service.

9.5.1 - COUNSELLING

Alan experienced a number of different counselling formats after initially seeking help, but he was most effusive about the CBT therapy that he received;

I think 100% CBT is the way forward (Alan Line 326) ..... It’s bizarre why they don’t do it straight away. It can save so much time, you’re essentially learning to be your own counsellor instead of saving it all up for a week (Alan Lines 327-29).

In total Alan had 13 sessions of CBT therapy, though his main concern appeared to be what would happen to him when his sessions finished if he was not cured. The answer he received was that he would have to go to the back of the queue, an answer he described as being “bizarre” (Alan Line 336).

9.5.2 - DIETICIANS

Alan’s experience of dietician services was short and limited; “I went to one session with the dietician and never went back. I found it quite patronising” (Alan Lines 321-22). Alan said; “I was very aware of the damage I was doing, I could completely understand what I should be doing was very different to what I was doing” (Alan Lines 375-77). In isolation, it could be argued that Alan did not give the sessions with the dietician a chance. From his point of view, he felt he did not need someone telling him what foods/calories he needed to eat, he needed solutions to actually make him eat. Alan’s comments echoed those of the other men interviewed who had similar experiences of dieticians.

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An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons
9.6 – MASCULINITY AND GAY MASCULINITY

Alan’s experience of masculinity was interesting and, from a traditional viewpoint, the absence of positive male role models can be the basis of a number of conclusions. Alan said that whilst growing up his best friend was his mother’s best friend whom he; “would always go to stay with her and chat and stuff” (Alan Lines 196-197). This was the person whom he first confided his eating disorder to. This friend/role model is indicative of Alan’s masculinity; firstly, this person is a female and secondly, they would have been older than Alan. With Alan mixing mainly with females growing up, it is perhaps no surprise that his friendship groups were mostly female and he rejected team and playground sport at school. Perhaps some of his sexual identity questions such as his coming out at the relatively early age of 15 may be attributed to a lack of traditional masculine role models, specifically in hiding emotions. A further albeit tenuous link to a lack of male roles models was in Alan’s use of English which at times could have been described as feminine. For example; “Everyone has a fat day when you just feel frumpy, your hair is sh*t or everything like that” (Alan Lines 516-17). Alan stated that he never knew his natural father, although there must have been some form of contact with his relatives as he found out he had a stepbrother around the time of his ED manifesting.

When asked directly about his opinions on masculinity, Alan responded by saying:

“I’ve never really thought about masculinity, I’d never really aspired, I never had any male figures in my life, I was brought up by women, my grandma, my mum and her female friends. All my friends, my closest friends have always been female...Masculinity isn’t something that I relied heavily on or been aware of. I don’t really think it affected the way that I ended up with anorexia. (Alan Lines 588-592).

The second part of this quotation is in keeping with findings of other studies (Murnen and Smolak, 1997; Meyer et al., 2001), which indicated that femininity, as opposed to masculinity, is a risk factor in EDs.

Often linked to masculinity and in light of what some of the other men in this study had talked about, sport was raised in relation to this. Alan stated; “God no I hated it, I despised it” (Alan Line 117). When asked if he felt this helped to isolate him he said; “yes it caused a lot of issues like playing sports with people. I would always try my hardest to get out of it” (Alan Lines 128-29). Although it may seem simplistic to link sport and masculinity, it
is one of the earliest ways in which boys can dominate others, and try to be ‘number one’, especially at school (Swain 2000). Studies such as Swain (2000) indicated that in junior school the boys display masculine hierarchies with break time football, a key indicator of hegemony. Girls were not encouraged to play nor were the boys, who within Connell's (1995) framework for Hegemonic Masculinity, would be classified as being subordinated.

Alan was openly gay, and as discussed previously (Section 9.3.1), his goal when exhibiting his behaviour was to be thin and feminine, as with young gay men of his age, he believed this was seen as alluring. In terms of traditional hegemonic masculinity, Alan had never aspired to it. After coming out, the concept of masculinity he focused on was based around gay community ideals for a young man, which Alan termed as a “TWINK”.

Traditionally a “TWINK” is seen as being a younger man with feminine characteristics (Schippers, 2007). Alan further defined this by adding an effeminate manner, a thin build, no body or facial hair, all which contributes to a youthful look. When it was suggested than to an outsider that sounded quite feminine, Alan stated:

Yes, that’s what you’re exactly supposed to be, passive and quiet and demur and sexualised and not smart, just dumb and young. It is very similar to how some people would see women – that pre-teen kind of image (Alan Lines 620-22).

This is not an ideal masculinity to aspire to, but studies indicate gay men are statistically more susceptible to EDs (Bramon-Bosch et al., 2000; Fassino et al., 2001; Russell and Keel, 2002), indicating the pressures on men in these groups and, in Alan’s case, on his appearance. When asked about this Alan stated:

Yes, and that’s your only real choice when you’re an eighteen-year-old gay, there’s no other stereotype for you to fit into, whereas if you’re a bit older then there are different gays you can choose to become (Alan Lines 624-26).

For a young man such as Alan, who found popularity within a community he felt accepted in, it must have been very difficult to stop when he realised he was harming himself, as this might have meant he would become isolated again. Alan added that despite stereotypical perceptions of gay men, he struggled to open up and talk to people over his emotions; “we don’t either, I don’t either. The massive struggle I had to talk about it but just bottled them up” (Alan Lines 706-07).
9.7 – LIVING LIFE WITH ANOREXIA

9.7.1 - SEXUAL PEAKS AND TROUGHS

Alan’s libido was affected by his illness which is in keeping with the findings of other studies (Hall et al., 1985; Cazzuffi et al., 2010; Agalusca et al., 2012). However, there seemed to be clear differences between Alan and the heterosexual men interviewed in this study, which can be attributed to his sexuality and the significance he placed on the need to have an extremely thin appearance to fit in with the masculinities expected within the gay community he associated with.

Alan reported that his libido decreased and increased at different times during his illness. He stated that whilst he was taking anti-depressants his libido was non-existent. He also believed that his libido was linked to his psychological feelings, stating:

I also find it’s linked to my feelings of self-worth I suppose. Everyone has a fat day when you just feel frumpy or your hair is sh*t or everything like that. It would be those days, it would be quite catastrophic and I had to really rein myself in and those were the days where it would be really low (Alan Lines 515-519).

Conversely, Alan also reported that after reaching 18, and being introduced to gay culture in a large city, his sexual activity increased. Being young and very thin he was seen as attractive, in his words; “men think you’re the centre of the world” (Alan Lines 638-39), in short, he found he was objectified. Alan found this to be very addictive as he suddenly became popular. Unlike heterosexual men, Alan found that his ED helped to reduce his isolation, suggesting;

In fact, if anything it’s the exact opposite [turning away from physical relationships] it was part of the addictive feature too, it was the skinnier I got the more I could flaunt myself, the more sexually promiscuous I became (Alan Lines 679-81).

However, before drawing conclusions, Alan’s promiscuity needs to be considered within the full context of his narrative. Alan reported he was promiscuous in a physical sense; “to this day it’s difficult for me to see sex as a romantic thing” (Alan Line 654). This indicates that whilst sexual isolation was different between Alan and the straight men in this study, other aspects of sexuality, such as an inability to form intimate relationships seems to be shared, a finding also reported in the literature (Lindblad et al., 2006).
9.7.2 - IMPULSIVITY, DESIRE AND MENTAL DEGRADATION

Alan felt that his behaviour whilst he was experiencing his ED was at times impulsive and he also felt that his judgement was impaired. Although he did not specify, he felt he had made a number of bad decisions due to the effects of the ED. He highlighted that he felt he was poor managing money and would make snap decisions. Alan spoke about his lifestyle which illustrated a rollercoaster cycle of emotions and behaviours, ranging from impulsivity, thrill/risk seeking, judgement issues and depression. Alan said;

It was self-perpetuating; obviously I’d starve myself for a week, go out, sleep with someone, do drugs whatever, and then my confidence would be through the roof, and then obviously that would sink eventually as reality hit again, and then I would just do it all over. It just spiralled. (Alan Lines 690-93)

Alan stated that his temper was affected during his ED; he felt that at any time he could and would snap at people and, when at his lowest ebb, he would; “shut myself away for days and yes all my relationships did struggle as I was horrible to be around” (Alan Lines 541-43). This is not uncommon for men with EDs as they often experience increased levels of shame, guilt, or anger (Lavender and Anderson, 2010).

9.7.3 - STUDYING AND WORKING WITH ANOREXIA

Continuing on the effects of his ED, Alan felt that his cognitive functioning was hampered, and exemplified this when talking about his time at university where his ED caused major problems, “it was very difficult going through university trying to write essays and trying to pay attention in class, when obviously you’re starved and all you can think about is food; all you think about is how cold you are, how tired you are” (Alan Lines 548-50). In fact, he had a number of problems at university, from not being able to complete his work, to ending up having to leave his course early due large part to his troubles with his ED. His comment re his pre-occupation with food which was prominent in his thoughts was reflected in Keys et al.’s (1950) study on starvation, whereby they noted that their participants became fixated on food, going so far as collecting recipes and cook books.

Alan’s reaction to his illness in terms of his employment is interesting. Alan stated that he was open about his experiences with his friends, yet when it comes to employment he would wait to see how he felt his ED would be received before fully disclosing. Mind
(2011) and Toth and Dewa (2014) highlighted unease with disclosing EDs to employers. When asked how he filled out disability forms for work, Alan stated; “I usually put other, at the bottom mental health, and then specifically mentioned it to my manager after I had been there a week and judged by their character that this was an issue” (Alan Lines 530-32). This causes the added issue of the potential ramifications in lying to his employers and Alan having to live with this and the possibility of being exposed.

Alan’s eating disorder has at times affected his capacity to work, due to the effects of stress, and also at the times when he changed his medication. This has resulted in capability investigations by his employer, although Alan rationalised this stating; “you can’t favour one person over someone else” (Alan Line 518). He also believed his employer and the managers in question had done their best to be helpful;

It is difficult and I can understand how that’s not for everyone as you might not have a manager as good as I did or you might not even want to be open and talk about it, and that’s your prerogative, but I was just lucky I suppose. (Alan Lines 521-524)

9.8 – EDS IN THE WIDER COMMUNITY

9.8.1 - PORTRAYALS OF EDS

In Alan’s experience, the portrayals of eating disorders can be quite negative, with reporting being patronising, whilst highlighting bad choices people make and trying to shock the audience. There is an almost superficial and stereotypical edge to the reporting that highlights weight loss and image. Alan said; “they do need to portray not just dumb little girls who want to sit in a small skirt and want to look like Giselle, to over simplify it people don’t yet know enough about how detailed it is” (Alan Lines 726-28). Added to this is Alan’s negative experience of giving a media interview to promote EDs (covered in 9.8.1.1). Alan believed in our society, as a whole EDs, like all mental health issues are largely ignored; “It’s a very British stiff upper lip, like kind of ignoring it, [as if] it doesn’t quite exist” (Alan Lines 694-95). Whilst Alan believed that our reticence to talk about feelings and emotions are not linked to EDs, he did believe that the stereotype of EDs is the domain of girls wanting, as he alluded to; “to look like Giselle [Gisele Bündchen Brazilian supermodel]” (Alan Line 727).
9.8.2 - HELP FROM CHARITIES

As with a number of men interviewed, Alan had active links with ED charities; in this case it was with Beat who he felt does; “great things” (Alan Line 712), especially in terms of research and publications. However, he suggested the charity was a little behind the times and not well organised, especially in their efforts in raising day to day awareness. He highlighted a charity sock promotion with the clothing site Jackamo, during an ED awareness week, the clothing company being well known for selling large sizes. Alan stated; “to me [it] seems a bit tongue in cheek to almost distasteful” (Alan Lines 718-19), indicating he was not happy with how the charity was raising funds. However, it perhaps could show a microcosm of some of the problems associated with EDs as a whole, in that they can affect anyone of any age or size. Whilst Alan suffered from anorexia, people have bulimia, binge eating disorder and other EDs.

Perhaps more worryingly was an experience Alan had when giving an interview for a national media source which had been set up by Beat. Alan stated the interviewer was not aware of and/or ignored the media guidelines published by Beat. Alan said;

This guy started asking me about what exact weight did I get down to, and I refused to do it, but he kicked off. I should have had an apology about that – I was like Beat should have told you about this, I’m not going to discuss it. (Alan Lines 736-39)

In Alan’s eyes Beat had not protected him and with Beat’s ambassador programme of volunteers, such as Alan and other men in this study, one must question the protection and training the charity gives.

9.9 – KEY POINT’S FROM ALAN’S SOTRY

- Personal and Background
  - Had never met his natural father.
  - Brought up in a primarily female environment until the age of 11 when his mother and her partner (who he did not get on with) moved in-together.
  - Exposed to dieting.
  - Bullied due to his weight.
Around age fifteen
  ▪ Found out his natural father had another child.
  ▪ His mother and partner had a child.
  ▪ Came out as gay.
  o Took active part in gay scene and played a young gay sex role, which led to sexual promiscuity.

• ED Manifestation
  o Food restriction.
  o Exercise.
  o Vomiting.
  o Laxatives.
  o Diet pills.
  o Amphetamines.

• Educational Experiences
  o Lost control of ED at university.
  o Eventually had to quit his studies due to his health.

• Reactions and Treatment Experiences
  o Felt his family’s reaction was not supportive, especially the comment made by his step father who brought up the cost of the food he wasted.
  o Had to wait two years for specific CBT, although he did receive general counselling from his college and GP.

• Work Experiences
  o Issues when changing anti-depressants, also gone through capability proceedings.
  o Does not inform employers of his ED unless he feels they will understand.

• ED Portrayals and ED Charities
  o Felt portrayals were female specific.
  o Happy with ED charities, however had a negative experience during a media interview and felt let down by, in this case, Beat. Was also unhappy with Beat’s association with Jackamo.
Alan seemed the most positive and bubbly of the men who participated. His background as a child was perhaps difficult and unconventional, having largely feminine role models and being isolated from his male peers due to his weight and lack of interest in sport.

Alan had to wait a long period to get specialist ED treatment which he felt was in part due to where he lived. Out of all of the men interviewed, Alan used the most varied and extreme methods to lose weight, and as a result of his anorexia he had to quit his degree course. However, as a gay man, Alan’s ED appeared to differ in some ways from the heterosexual men in the study. His goal was different (to become thin) and the closer he came to this goal the sexual arousal of his peers within the gay community increased as did his popularity. This popularity from Alan practising promiscuous sex, had led him to detach sex from love; however it may in some way partially explain his use of extreme methods to lose weight as it was linked to increasing his popularity. Alan was a keen activist for male EDs and has helped both of the main charities even after having a negative media experience.

In hindsight I feel that I scratched the surface with Alan’s interview and that, after looking at and analysing the other interviews, there were many questions which I should have asked. Co-construction or a second interview would have been an ideal way of getting beneath the surface and expanding upon Alan’s experiences.
CHAPTER 10 - RUSSELL’S STORY

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS
The interview with Russell highlighted a number of interesting points with regard to his life living with an ED. At the time of the interview he was waiting for the new academic year to begin to go back into full-time education. He had finished/put his career on hold due to the physical nature of elements of his work and his inability, because of his ED, to carry these out.

At the time of the interview, conducted via the telephone, Russell was in his early thirties. Russell also saw himself as different to others who had an ED, stating; “I don’t fit the normal anorexia pattern. I don’t know if it’s my age or it’s the fact that it manifested itself so later in life” (Russell Lines 1015-16). He elaborated, talking about how his ED manifested and how his life in general, he felt, never naturally fitted into the way EDs are perceived by society. However, whilst there are elements of Russell’s background and ED which appear to diverge from the stories of other men interviewed, other elements share commonality.

Russell indicated that he had only had one episode of ED behaviour which manifested in his late twenties. In contrast to other men who have had an ED, Russell appeared to be much less isolated, reporting no major issues growing up or experiencing a crisis over his masculinity. At the time of the interview Russell was in a heterosexual relationship which, based upon comments he made regarding sex and his libido, I assumed was long term. His relationship and comments are discussed in the main body of this analysis. However, although some of the traits identified above could be out of sync with stereotypical presentations of men with EDs, Russell’s narrative highlighted an adherence to rigidity, rules and an internal timetable of doing things that appeared to be extreme, as were some of the perfectionist tendencies he described. Likewise, his behaviour around eating, which revolved around eating calorie sparse food, rather than next to no food at all, also differed from the patterns of male EDs often reported on within literature. Russell appeared aware of this, describing himself as; “I am stupidly thin and I eat enough to function and survive” (Russell Lines 109-110), and going on to make a comparison between his own and his perception of others’ behaviour; “I’m not the 16-year-old [girl] sitting in the corner shaking at the thought of a lettuce leaf,” (Russell Lines 205-06). Russell went on to report
that he does not have a major issue with eating per se, but that he would eat three meals per day; “bulking out on low calorie food and then drinking an awful lot” (Russell Lines 1033-34). Russell also exercised excessively to strict routines. Russell’s story in many ways indicated variances in anorexia which are not often discussed.

10.2 – BACKGROUND

Russell originated and lived in an area approximately one hour’s commute from a major city. His family when growing up consisted of his mother, father and older brother. Both his mother and father were professionals and he described his background as middle class and rural.

Russell’s mother and father have a history, stemming back at least as far as his childhood, of being overweight. Russell said that his brother’s weight growing up was normal and healthy. His father’s job meant a long daily commute to work (at least two hours travel) and as a result Russell felt closer to his mother stating; “we were basically raised by my mum in a perfect loving stable family home” (Russell Lines 259-60). With regard to his mother, Russell later went on to say; “she mothers me more than she mothers my brother” (Russell Line 1160). Russell felt his mother’s behaviour towards him was due to two near death experiences; one in the process of his birth and the second when he was a toddler.

Russell could not remember either incident stating his therapist had not felt these important, but there is literature to suggest children from a very young age do harbour memories, both conscious and unconscious (Freud, 2010). Likewise, in light of these experiences, his mother could have felt over-protective towards Russell, transferring these feeling on to him (Bateman and Holmes, 1995). He could also have been ‘mothered’ because he is the youngest. Of his father he said; “we’ve never been that close and we’ve never really shared much or connected that much” (Russell Lines 450-51). Russell felt this was probably due to his father’s absence due to his work. At the time of his interview Russell indicated the situation remained the same; his mother was able to help him much more because she had retired, whereas his father was still working.

Russell had an older brother with whom he has a good relationship, although living in another part of the country they regularly speak on the phone. Russell described his brother as being laid-back, and when talking about telling his brother about anorexia he said;
It’s just water off a duck’s back to him whereas I’ve always searched for my role in life, my purpose in life. I’ve always wanted to know why and things and so I think because I’ve been more specific in finding out, I must know what I’m doing. Now I think I’m slightly more prone to the route into anorexia that I took and my brother is just laid-back and not really caring about much (Russell Lines 480-85).

However, whilst Russell made such comparisons, this image of a laid-back brother does not necessarily mean that he has never suffered from mental health issues. Before his marriage, Russell’s brother consulted mental health services because of concerns about his parent’s reactions to some choices he made which they did not know about. For example, riding motorbikes and having tattoos, his brother was also concerned about his fiancé/wife’s reaction. Without having his brother’s version of events this is obviously difficult to analyse. It potentially indicates a strictness or reserve on the part of their parents, which is potentially at odds with Russell’s comments about his “perfect, loving stable family home” (Russell Lines 259-60). This incident also indicates the relationship between Russell, his brother and their parents as still being between parents and children, rather than as adults. Whilst understandable that he may worry about his fiancé’s reaction, it is puzzling that he was more concerned about his parent’s reaction when marriage was about him and his fiancé. With regard to Russell, this strictness or reserve could be considered in direct contrast to other elements of Russell’s narrative, especially around food. Russell highlighted how he thought his personality was more conducive to anorexia as opposed to his brother’s, which made sense given certain identified personality characteristics such as obsessive traits, which are quite often linked to the body and eating (Fassino et al., 2001). Yet, even though his brother was described as being laid-back and carefree he was still unable to deal with certain events, albeit at a stressful, if joyous, point in his life.

10.2.1 - FREE ACCESS TO THE PANTRY

The issues alluded to above re Russell’s brother’s worries and their parents’ influence/control are in direct contrast with the families’ attitude to food. Russell described himself growing up as; “I was always the fat kid” (Russell Line 1225), and it is perhaps no surprise considering the family’s eating habits whilst he was growing up. Whilst not disordered within an ED context, Russell’s narrative painted a picture of eating junk food, there being no portion controls and having access to an assembly line of unhealthy snacks.
With both his parents working, it is perhaps understandable that meals consisted generally of; “junk food like fish fingers and chips that kind of thing!” (Russell Line 218-19). However, Russell also had the freedom of the pantry to graze between and after meals;

Food was never really controlled around our house, you would wander into my parents’ house eating a chocolate bar and then 6 packets would appear in the cupboard in case you got hungry again. (Russell Lines 226-28)

This total freedom resulted in Russell reflecting; “I would have dinner then polish my way through packets of crisps and biscuits, so eating for me has never been a problem, it’s just knowing how to stop” (Russell Lines 229-30). This freedom to eat what and when he wanted could be a reason for the development of Russell’s rigidity and adherence to rules which later took over his life, and to a large part still controlled his life at the point of his interview.

**10.2.2 - BULLIED OR NOT BULLIED? THAT IS THE QUESTION**

As a child, Russell stated that he was always conscious of his size, and that he had memories of being bigger than the other children, most notably in primary school. Primarily, he remembered this came to the fore at school sports days when he would come last in the event he was selected for. Russell noted his relief in one year when a peer, who was bigger than him, was in the same event and Russell was able to finish second to last. At secondary school, Russell recalled that whilst being larger than most people, there were more children of a similar size to him than at primary school. Russell felt that whilst he was not happy with his weight it was not a major issue growing up.

The same can be said of bullying. When discussing this, Russell stated that his mum said that he was; “bullied religiously by some of the kids in my year. I don’t remember them in the slightest as anything more than just friends” (Russell Lines 296-98). Assuming that his mother was correct, this would indicate that Russell was either extremely naive as a child or that he has repressed such memories. Russell’s mother worked at the primary school he attended so would have perhaps been in a position to note any bullying. However, it must be noted that as Russell did not remember these episodes, there is no way of knowing if him and his mother had differing perceptions of what was happening or their interpretations of other children’s behaviour. Likewise, it is difficult to know if episodes of
bullying were down to his size or the fact that his mum worked at the school. Russell observed that these episodes must not have been physical as he would have remembered them.

Russell did recall one incident of bullying which involved a teacher, his head teacher, who asked him in front of a class of his peers; “when I was due?” (Russell Line 310). Russell said this was; “the only bit of bullying and name calling I can remember at all!” (Russell Lines 314-15). All of this took place at primary school, as when attending secondary school Russell believed there were children who were easier targets than he was, and as such they were bullied and he was not. Reflecting upon his school experiences Russell said;

I’m sure there would have been a bit of name calling here or there from time to time, but I wasn’t certainly picked on all the time and if there was it didn’t really have any lasting effect in terms of I wasn’t dreading going to school. (Russell Lines 317-20)

Russell reported that he never felt isolated from his peers on a social level, stating; “I had a perfectly good group of friends. We hung out, we went to the cinema; we did school teeny type things really” (Russell Lines 339-41). However, he did state that geographically he was slightly isolated, as he lived away from the school and his friends.

In terms of Russell’s background and predating an ED the only apparent factor which Russell had in common with evidence available in the literature was being overweight in childhood (Cooperman, 2000; Fernández-Aranda et al., 2004; Gueguen et al., 2012). Russell did not report what he felt were significant or continuing episodes of bullying, nor did he report social isolation. It would therefore appear from his narrative that of the risk factors for anorexia weight and body image concerns were predominant.

10.2.3 - ED BEGINNINGS, HEALTH GOING UP IN SMOKE

The being overweight that Russell reported during his years in primary and secondary education was something that was rectified by the time he had finished his A Levels. Unfortunately, Russell did not expand on what prompted him to lose the weight or how he achieved this, but he did say “I was fat all the way up to my A levels and then I lost the
weight, but I still saw myself as a fat kid with a big fat belly and the man boobs.” (Russell Lines 378-79).

Russell indicated that approximately four years before the interview took place he had made a conscious decision to quit smoking and decided that whilst he did this he may as well get fit at the same time. It is pure speculation as to why Russell smoked, however studies have indicated nicotine as an appetite suppressant (Mineur et al., 2011). It may have been a way for him once he had lost weight in his teens to keep it off. Russell gave up smoking and started to exercise, mainly rowing and running. He stated that at the end of approximately one year he was basically the same body shape;

I started rowing and running and things when exercising, and they were saying ‘do all this rowing it works great it works every muscle in your body and you’ll end up with a 6 pack’. And a year later it was nope I’m still a big fat kid. (Russell Lines 381-84)

Looking dispassionately at such a statement it is difficult to believe that after a year Russell’s body was still the same. There could be a number of reasons for this, for example the level of effort he was putting into exercising and/or the amount of food he was eating during this period was incompatible with losing weight. Another explanation could be an indication of his poor body image and unrealistic expectations which were perhaps his beliefs at the start of this period. Russell himself questioned this in the following comment; “You read all this stuff on the internet and if you do all this exercise and you’ll become this super human wotsit and it just didn’t add up” (Russell Lines 13-15).

10.2.4 - BODY IMAGE DISSATISFACTION

Russell’s ED seemed to be rooted within his poor body image. He reported that as a child he saw that he was bigger than other children and even after losing weight in his late teens he still saw himself as being fat, especially in his chest and stomach areas. Russell said that he; “did quite often compare” (Russell Line 380) himself to other people, and he believed his dissatisfaction with his body was a reason for the onset of his ED behaviours. This dissatisfaction became more acute after a year of exercise and not being able to achieve his goals. This lead to Russell taking more control over his diet, and this was done using a mobile phone app called My Fitness Pal.
My Fitness Pal is an application which tracks the calories a person consumes and burns, with the user inputting food consumed and exercise taken. The app then keeps a log and measures this against the user’s goals which can be to lose, maintain or gain weight. At any point in the day the user can see how many calories have been taken in, burnt or how many calories are allowed within the daily limits to achieve the user’s goal. For Russell, the app soon became problematic as the daily target and goal setting soon became a personal challenge for him to stay underneath what was suggested. Additionally, he was also able to control his portion sizes and grazing, and soon found his weight dropping which fuelled his behaviour;

The app was very good to begin with but it sort of reached this point that it all became a bit of a challenge, that you’ve done this much exercise today you’ve got this many calories to burn off or to eat so it would be useful (Russell Lines 30-32).

Russell reached a point where he was weighing herbs and spices to put into the app to get the calorific content. Russell said; “My weight went down and down and down and down, getting lower and lower until physically I couldn’t exercise any more. It just became sort of all encompassing” (Russell Lines 40-41). Russell started to rationalise that the calories he was able to cut underneath the app’s target as a positive;

By the time you add that all up [calories] at the end of the week you’re thinking that’s one and half days of food that I haven’t eaten, but your brain is saying that’s brilliant; because it has set this limit and your underneath it (Russell Lines 1447-50).

My entire life was revolving around mass exercise to do this app and it got more and more nuts, and it got to the point where I just literally said I’ve got to stop because my body can’t. I was doing an hour’s row every day and my body was just going I can’t row for an hour everyday anymore; I don’t have the strength or the muscle to do it (Russell Lines 44-45).

It could be suggested Russell lost control when using the app, but it could also be argued the app allowed him to take more control. Russell said of the app “there’s a lot of things now entrenched in me and my way of thinking which has come about because of the rigidity of the app” (Russell Line 48-50). It is clear to a certain degree Russell held the app responsible for his ED, but it was not the app that was rigid, it was his adherence to it. In fact, his brother used the app for a short period, but did not find it helpful because he kept forgetting to update it. It could be suggested Russell’s rigidity and his need to abide by
rules would predispose the app becoming an instrument by which he could exercise his control, and one ultimately that had the potential to control him.

10.3 – ED TAKES CONTROL: MANIFESTATION AND EFFECTS

Russell felt that the goal of his ED was always to tone his body and not to lose weight. His dissatisfaction with his body image did lead him to state that he felt if he stopped exercising parts of his body, most notably his stomach, he would get fat. This perhaps indicated the powerful effects of excessive exercise which gives the person with the ED justification to exercise to lose weight and at the same time justification to avoid weight gain. Russell’s body dissatisfaction led him, as discussed previously, to start to restrict his food intake. In a stereotypical case of food restriction this involves quantities as well as calories. For Russell this restriction was different because he focused on reducing the calories consumed as opposed to portion size;

I would eat 3 perfectly normal meals a day in terms of the amount of food. I would have a mound of salad. At the worst, I was eating about 900 calories a day but it was 3 big meals 300 calories a meal, but they were bulking out on low calorie food and then drinking an awful lot (Russell Lines 1030-34).

Russell believed his upbringing of having large portion sizes and clearing the plate was responsible for his continuation of eating meals, albeit extremely low-calorie ones. He then started to cut all foods out of his diet which had more than 100 calories in them. Combined with this, Russell would row for at least one hour a day. This regime saw him lose over a third of his body weight with him physically unable to complete important elements of his main job role, which involved tasks that depended upon heavy lifting. Russell also reported problems with mental processes, which his doctor thought was due to a lack of food (discussed in Section 10.3.2).

Russell recalled an episode where he ate something whilst out that he thought was low calorie. When he later inputted the food he had eaten into the app he found it was the opposite. Russell said; “it panicked me so much I ended up having a second row that day to burn it off and it literally got completely out of control” (Russell Lines 1463-64).

Eventually Russell stopped using his My Fitness Pal app and he also threw away his rowing machine because in his words he; “wasn’t physically strong enough to row

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anymore” (Russell Lines 1465-66). For Russell, though, this was too late as a lot of damage had been done, and his resultant treatment saw him being banned from engaging in exercise.

Apart from the problems he reported with his mental processes and wellbeing, Russell was also sent for scans due to his low weight and was subsequently diagnosed with Osteopenia and was borderline for a full diagnosis of Osteoporosis. He lamented that despite being told this information he never had a eureka moment where he saw how the ED was negatively affecting his body; “you sort of, kind of, think it should have been that kind of life changing moment where you almost came home and started chomping on the chocolate cake to say enough is enough, but I didn’t” (Russell Lines 124-26).

Russell spoke of his use of diversion/distraction strategies which although he used as a way of dealing with his ED, showed an all or nothing nature to his character. Russell said;

I went through a phase where every inch in my house, every wall space in my house had to be covered with modern art and stuff. I had quite a nice art collection, but no wall space. I ran out of that and I thought I’ll get into movies and I started watching a phenomenal amount of films and it’s all just ways of distracting myself and it was a way of coping with the ‘what am I going to do? (Russell Lines 1397-1402)

The ‘what am I going to do’ related to his obsessiveness with food, and in order to cope with this he had to substitute it with other behaviours which could be considered as extreme.

10.3.1 - A HAPPY SEX LIFE BEFORE ANNA ARRIVED!

Unlike a number of the other men interviewed Russell did not report any significant issues with isolation, and in terms of his sex life there was nothing said in the interview to assume that before his illness it, or even his sexuality, was a concern. However, Russell stated that after his ED began he felt a drop in his libido;

“I have no interest in it. I can walk down the street and think she’s attractive or whatever but there’s definitely no real interest in it” (Russell Lines 973-74). Before his ED he said; “before I had a nice happy delightful sex life and currently now the thought of it doesn’t interest me if that makes sense” (Russell Lines 978-79).
Russell also stated that he enjoyed sex for both the pleasure giving and receiving aspects and not just for his own gratification. For other men interviewed the lack of sexual interest did not really cause any immediate problems in their lives. For Russell, it was different as at the time of his interview he was in what appeared to be a long-term relationship. He said; “I still find my girlfriend attractive and we still have the odd random bit of sex, but I’m just as happy watching TV rather than have an early night with her” (Russell Lines 980-81). Russell believed this to be an issue as he felt that at times she was quite annoyed with him;

   Annoyed I think because I am conscious of it and because you can obviously tell she’s itching you to kind of force yourself into it, but at the same time I’m not that bothered about it if that makes sense. It’s definitely more instigated by her than me these days (Russell Lines 984-87).

Although I did not explore the notion of forcing himself to have sex it is an interesting dynamic for further investigation when looking at relationships within EDs, both from the stereotypical views of male dominance within sexual relations, to the effects on masculinity when sexual interest is not present. A further interesting element of this part of Russell’s narrative was that this was the only time in the entire interview that he mentioned his girlfriend. This in itself can be construed from a number of positions, from him protecting her, to him being extremely self-absorbed, or to him not thinking she is part of his ED.

10.3.2 - PERFECTION, TEMPER, AGGRESSION AND MENTAL FOG

Russell noticed that his behaviour changed or got more extreme with the progression of his ED, citing that he was quite impulsive; although this is the polar opposite of his rigidity around food, and he had an all or nothing personality which caused him to get quite “stroppy” (Russell Line 1056) if not able to get his way. Russell believed his stroppiness led him to be more aware of non-physical aggressiveness on his part, especially when his routines were affected. Russell stated that when out shopping, if people were, in his opinion, dragging their heels he would become;

   A bit rash, a bit angry and slightly aggressive. My life was the most important thing to me and anyone who slightly got in the way of that would get grief from me until they either got out of my life or fell into line (Russell Lines 1070-72)
The behaviours which Russell described in the previous quote are exemplified by two incidents from his narrative. The first incident involved his dealings with the NHS, when he refused the mental health team entry to his home, and subsequently stopped using mental health services. Secondly, when describing the breakdown of his relationship with his former nutritionist, he justified this by calling her a “tree hugging hippie” (Russell Line 917).

Insulting a nutritionist, whose job is to help, may seem an ill-informed decision and Russell noted that his decision making in late afternoons became; “foggy” (Russell Line 1085). He stated;

I didn’t have a clue. I would be in a complete daze it was absolutely bizarre. Mornings were alright I’d be perfectly happy, nice and jumping around and life was good. In the afternoons I would just go off completely downhill and there were times where I would go back to bed (Russell Lines 1094-97).

It was because of these ‘downhill’ episodes, as well as other reasons, Russell decided to give up his job so he did not get to a point where people were endangered. This mental shut down resulted in Russell consulting his doctor for advice. His doctor believed it was due to low blood pressure from a combination of ‘sugar spikes’ and ‘lack of food’. However, Russell felt that it was due to him having artificial sweeteners in drinks. When he cut out these from his diet he said the ‘foggy’ spells stopped. He did add; “I’m sure it’s just coincidence and I am sure the doc is right and it’s probably a blood pressure thing related to the amount of food I was eating” (Russell Lines 1114-16). Russell’s statement perhaps demonstrated misgivings about the official reason given; it could be construed that he was looking for a reason for these ‘downhill’ periods which was not related to his ED behaviours.

Such behaviour is common in people diagnosed with anorexia. For example, they generally score highly on perfectionism (Andersen and Mickalide, 1983) and rigidity tests (Murray et al., 2014). Throughout the duration of his narrative Russell spoke of his rigidity and a highly perfectionist streak manifesting through his ED behaviour. This has resulted in Russell embarking on his own treatment plan after deciding not to pursue NHS treatment (discussed in Section 10.4). Russell’s perfectionism was also highlighted when he spoke about an academic course that he had recently completed where he scored 97% overall and said; “I was really angry, two of the modules I got 98% on them not 100%
because I had made stupid errors” (Russell Lines 1376-77). On discussing this with his therapist, Russell’s reaction to the argument that to get such a score was a great result with much sacrifice was; “Yeah!” (Russell Line 1381). The interpretation of this comment, together with the audio recording, perhaps signifies he felt the therapist’s perception of the situation was incorrect; the therapist looking at the positive, whilst Russell looked at it from the viewpoint of the perfectionist.

10.3.3 - WORKING WITH ANOREXIA

Russell’s ED deteriorated to a point where he had to give up his main job. Russell was self-employed and he was able to initially work around his meal time routines. He reflected that in a regular 9-5 job he did not think he would be able to cope because of his rigidity around his exercise and food. While stating his occupation might compromise his anonymity, suffice to say his work involved him handling heavy objects, working in different locations and at other times being responsible for the safety of others. He said; “it literally got to a point because I was getting thinner and thinner and weaker and weaker the physical side of it started to affect my job, and it literally got to a point where I couldn’t physically do the job anymore” (Russell Lines 517-19). The whole issue around employment opens up an interesting area for future research, especially in terms of how people manage their ED in different employment situations.

Although Russell noted, as discussed previously, a change in his cognitive skills, he stated by the time it got bad enough that it may have affected his judgement at work he had already stopped working because he physically could not do his job;

I’ve had afternoons where I’ve literally just sat in a fog, not really caring about anything or not being able to focus on anything and all that kind of stuff and I thankfully wasn’t xxxxxx [working] at that point, but I was also conscious enough of it to know that I wasn’t in the right head space (Russell Line 601-05).

It must be noted that by the time Russell may have noticed the erosion of his cognitive ability as being potentially dangerous, he may have already reached a point where he was a danger to people due to the questions surrounding self-awareness and perceptions based upon the effects of his ED. There is no way of knowing if Russell’s choice was the correct one, but it was the right choice for him at that given time.
10.4 – BARRED DOORS & QUACKS: RUSSELL’S TREATMENT JOURNEY

Things got to such a point both physically and mentally for Russell that he sought help; “I realised things weren’t great and they were getting out of control so I went to see my GP who said ‘no problem we will refer you to the local eating disorder service clinic’” (Russell Lines 671-773). Reaching out for help appeared to be his own decision with no mention of pressure or comments from other people. Russell was then contacted by his local mental health team. This was the starting point in an episode detailed within this section which illustrates many issues for further debate away from this thesis. For example, the issue of implementing client-centred care. Russell said that due to the rigidity of his rules he had to be at home at certain points in the day so he could have his meals and exercise. If any event interrupted his routines he would have panic and anxiety issues. As such he asked if they could come to his home for his first appointment, rather than him going to see the mental health team, which he thought would cause problems in his routine. This was agreed and a time and date were set. Before the appointment was set Russell issued strict guidelines for when he was available;

I said to them ‘I row between this time and this time. I have lunch between this time and that time, do not come between those times because I will not let you into my house because I will be busy and it’s very important that you don’t do it’. So, it was agreed that they would come at something like half two (Russell Lines 688-93).

At a quarter to two, on the appointed day, forty-five minutes before the appointment and at a time when they had been told they would not be received, the mental health team knocked on Russell’s door. Russell refused to let them into his home as he was in the middle of his lunch. Russell phoned his mother, who came to his house to deal with the problem as, in Russell’s words, he told her; “I can’t deal with it” (Russell Line 696). Russell said his mother asked them why they had come to the appointment so early and was told that;

They came early because I need to be shown that I can give up control and things would be alright. I totally flipped at this and refused to have anything to do with them ever again so I walked away from NHS therapy (Russell Lines 698-700).
Neither side came out of this episode unscathed. Russell’s need for control and his rigidity with regard to his ED are clearly illustrated, in that even when taking his first steps to treatment he was not willing to break his routine. Regarding the community mental health team, it shows a lack of respect and, it could be suggested, arrogance when dealing with a person whom they had never met. Russell said on reflection that if the mental health team had said:

‘We are really sorry we know we’re here a bit early we’re here because of this that and the other’ I might have been okay with it. I would have probably said ‘if you can go sit and wait in my lounge for 40 minutes or whatever while I eat my lunch’, but just to turn up and play this power game trying to show me that I can give up control and life wouldn’t be…. that’s not it (Russell Lines 775-80).

He said of the mental health workers;

They completely misjudged the situation and if I am 100% honest it set me back quite a lot because it turned me off therapy and seeking help for quite a while. As I said I had got to this point, afterwards that no one can be trusted, no one can understand my problem so I’ll just if I’m going to sort myself I need to do it on my own (Russell Lines 781-85).

A further dynamic which surfaced in this episode was Russell’s decision to phone his mother to sort out the situation. To an observer it seems a much more amicable solution could have been found if he had dealt with the issue himself, opened the door and spoke to the mental health workers. As discussed previously, Russell felt that he was unable to do this and this does indicate how the effects of the ED can affect judgement and decision making (Treasure 2005). However, it could be argued that calling in his mother, and asking her to drop everything, to sort out his problem is indicative of psychological regression or immaturity.

Having lost total trust in the NHS and, in his own words, used it; “as a sort of excuse for a while to not have therapy” (Russell Line 701), Russell lived in a state of limbo, being known to the NHS, but not using their services. This lasted for approximately eighteen months before he made efforts to re-engage after his mother had asked him to do so, this time through private health care, because; “For all I know I could have the world’s greatest NHS mental health team literally down the road and I just don’t want anything to do with them” (Russell Lines 871-72).

He went about engaging in therapy in a black and white judgemental way;
I then started doing some investigation into therapy and spent ages looking for therapists on line that were local to me. Most of the therapists, I know, it’s just a picture on a website, but they all looked like 60-year-old ladies who wanted a hobby to become a therapist and I would just look at the pictures and think ‘you look a bit too much like a mother, you’re just going to try and mother me’. I spent months trying to find a therapist (Russell Lines 709-14).

Having such stringent criteria may be interpreted as a way of delaying the onset of help and a desire to continue the routines and rituals. It also can be associated with Russell’s perfectionism where he also stated that he had do to everything to the best of his ability, which makes jobs a lot longer than they need be.

Russell eventually chose a therapist who was much younger and who, on her site, said she specialised in EDs. He said that working with her had; “completely changed my life and I’ve certainly realised a lot of things about why I am who I am, and why I see the world the way I do” (Russell Lines 723-24). Russell believed his therapy allowed him to become less regimented, so much so that he was able to put his routine to one side in regards to having meals at home at specific times. He also stated in hindsight that he saw how he could have handled the NHS appointment much better. However, he said that he felt his treatment with his therapist was about taking; “baby steps” and; “not the all or nothing that the NHS were trying to force onto me” (Russell Line 836). This comment indicated that for Russell it was important that he played a key role in any treatment decisions and highlighted how a one cap fits all approach may not work. Whilst Russell’s foray into choosing his own therapist was successful, this was not the case when finding a nutritionist to help with his food intake. It was on the recommendation of his therapist, that he engaged a nutritionist.

This initially did not work, as Russell did not like the nutritionist’s way of dealing with things and felt he was not listened to. Russell believed the advice given was to eat more to gain weight, with the nutritionist’s aim for him being to eat whatever he wanted without guilt. Russell said that the nutritionist could not understand that he did eat and was not scared to eat per se, but his diet consisted of lots of low calorie food. Russell believed increasing the portion size would mean him spending more and more time eating larger quantities of food when he had issues regarding portion control; “I know I need to put on weight but there’s got to be a better way than just slamming porridge down my mouth for an hour” (Russell Lines 196-97).
Whilst Russell seeking a different approach is not surprising, considering his desire to remain in control, it was surprising that he ended their relationship in manner he did. Russell said; “it didn’t end well because I called her a quack” (Russell Line 934). Considering that the nutritionist was doing her job, Russell’s comment could be seen as being extremely rude and childish. This could be interpreted in a number of ways. It could be an extension of his anger at the sessions not working, perfectionist traits, a threat to his control, a lack of thought about the feelings of another human being, and/or a lack of co-operation which is found to be higher in anorexic men than women (Fassino et al., 2001). Conversely, there is evidence to suggest people who have a diagnosis of anorexia have a tendency to please others rather than offending (Treasure, 2005). Russell said of his personality; “I come from a slightly scientific background, that I like to know why” (Russell Lines 917-18). Russell sought out a second dietician who, he believed, was more scientific than the first; “She [dietician] is slightly more annoying in that because she’s a proper dietician and not a nutritional therapist, she’s got certificates on the walls; she feels more like a doctor so there isn’t quite the relationship there” (Russell Lines 942-45)

This was an interesting comment as he saw this dietician as being much more professional because of the Institutionalised Cultural Capital gained from the certificates on the wall (Bourdieu, 1986). However, he was not able to have a close working relationship with her, but he remained a patient because the dietician’s mantra was; “I will explain to you why this is better for you, rather than I’m here to make you eat whatever you want to eat and don’t panic about it” (Russell Lines 954-56). This is another example of his need for rigidity with clear boundaries and rules, and is further illustrated in the following quote;

I could email the nutritional therapist to say ‘I’m feeling a craving about this or I’m doing this or the other’ and she was there to help me, whereas the dietician is very structured. ‘You come to our session I tell you what to eat, you go away and eat it and then you come back to our session’. I can’t email her in between and say I’ve just been told my bone density is through the floor I need to eat more calcium can you help me? You have to wait until the next session... It’s a little bit more structured and a little bit too serious. It’s more what I need! (Russell Lines 946-54)

From the comment above it could also be suggested the dietician was not trying to simply make him eat more food, but inform him of good choices, thereby allowing him to maintain a certain amount of control.
10.4.1 - BONE DENSITY ISSUES – WHY NOT TAKE UP RUNNING!

Whilst Russell was able to make steps going forward in his recovery process, he also received advice which was contradictory and confusing, and perhaps indicates a problem in the approach of using both the private and public health sectors. Russell was advised, after his bone density scans, that a good way of increasing bone strength was to take up running, due to it being an impact exercise. Russell said; “my body isn’t physically capable and I don’t have the extra fat to burn off with exercising,” (Russell Lines 74-75) which is an understandable concern given his ED. His doubts about the advice were further complicated by; “my GP’s been saying ‘you ought to be thinking about doing some running to help you’ and the dietician saying ‘for the love of God don’t do any exercise’ and it’s ‘what am I meant to do?’” (Russell Lines 75-78). Being advised to exercise when at a low weight is perplexing, taking into consideration Mehler et al. (2008) study’s title “High Risk of Osteoporosis in Male Patients with Eating Disorders” or Carpintero et al. (2013) whose case study highlighted a patient with fractures to the femur caused by anorexia. One explanation could be the disjointed approach to his treatment, with him receiving treatment within the NHS (GP and bone density scans) and the private sector (counselling/therapy and dietician). After having scans, it is understandable Russell was given general information about improving his bone density, but it does not make sense for his GP, who is fully aware of his case, to encourage running as a course of action. While there is some evidence as to GPs being a barrier to treatment (Paterson, 2004), Russell’s experience would suggest professional ignorance in terms of EDs, and of health in general, on the part of his GP. Perhaps Russell misunderstood what his GP fully meant. He may have thought this himself as he said during the interview he intended to speak to his doctor again about it. Exercise was a major concern for Russell, fearing that starting to exercise again would lead to another loss of control and bout of anorexia; “the last thing on earth I want to do at the moment is to start running especially as I know where exercise can potentially lead with me” (Russell Lines 99-100).

10.5 – THE MASCULINITY QUESTION

Masculinity was not something that worried Russell. Although he said he had a history of body image concerns he also stated; “I don’t feel any less of a man!” (Russell Lines 386-
In his narrative Russell focused on his experiences of the ED in his late twenties, and although it is known that he lost his childhood weight during his A Levels, the information relating to the period after this and preceding his ED is scant. It has to be assumed that everything was normal, in terms of relationships, work and life in general. As such Russell’s masculinity, as he stated, was not a concern. However, Russell did make some points about his background when talking about masculinity which are illuminating and indicate some of the traits discussed earlier in this analysis regarding perfectionism. Russell was asked if he was sporty, his immediate answer was; “to a point, I was never sporty in terms of I would never be sporting a career as a professional sports person.” (Russell Line 348). Russell’s perfectionism is clearly seen in this quote, where he clearly indicated you can only be considered sporty if you achieve the level of professional. Russell finished the previous quote by saying “I always liked playing football and cricket and that kind of thing, so I was sporty to a point.” (Russell Lines 349-50) This shows how enjoyment in doing something was almost seen by Russell as being a secondary factor to the ability to succeed. Russell also stated that he enjoyed running at school which he felt was strange because of his size. However, it seems to be his constructed capital in terms of what a runner should look like and may be the underlying text of his comment; whilst people of all shapes and sizes enjoy running, the best runners generally conform to specific body styles for their particular events.

This comparison to others goes beyond a sporting sense. Russell spoke of his body image dissatisfaction and said; “I did quite often compare myself [to others] ... and that’s one of the reasons that it did start to manifest itself” (Russell Lines 380-81). Although Russell never felt any less of a man, his need to keep comparing his body to other men and his desire to be toned raises questions as to how comfortable he was with his masculinity.

A number of the men interviewed were not stereotypical male risk takers, specifically relating to contact sports at school. Russell was no exception to this and said that he did not enjoy it because his P.E. teacher, who had played rugby union at a very high level, was extremely serious about it. In light of this, Russell believed someone would have been injured during play. It could be argued this was a sensible course of action by Russell, or that he was risk averse. This was contradictory as Russell had previously indicated that he put capability at sport before enjoyment. A teacher who took sport seriously would have
met with Russell’s approval. Josephus wrote about the Roman army “their drills bloodless battles, their battles bloody drills.” (Josephus, 1981 p. 195), illustrating that by making training as close to combat as possible, in fact made combat easier. This is a mantra has survived the centuries and one would perhaps expect someone with a perfectionist nature to subscribe to this belief and be quite happy for a teacher/coach to be extremely serious. However, before any conclusions can be drawn linking Russell to being risk averse, one must be aware that his main source of employment income as an adult was in a job which had elevated levels of risk, yet it did not have the continued physicality of contact sports.

10.6 – REACTIONS TO AN ED: SUPPORT OR OSTRACISM?

10.6.1 - FRIENDS

When Russell told his friends of his ED there was generally a sense of shock. Despite the fact that he lost a considerable amount of weight, it is perhaps something in our culture which prevents people from asking ‘are you ok?’ Russell certainly commented upon this saying; “people have never actually really asked me about it, they’ve just looked at me and done a ‘he’ll talk to us if he wants to’” (Russell Lines 407-09). Russell noted that he generally got a better reaction to his ED from his female rather than male friends, stating that his female friends wanted to mother him and were very protective. In contrast, his male friends were unsure how to treat him and he felt their behaviour could be due to; “masculinity” (Russell Line 429) and likened it to how people may treat children. Russell added that he felt his friends were at times; “treading on eggshells” (Russell Line 415) around him. He indicated that this was frustrating saying; “it’s like treat me normally I’m still the same person I was, I’m just a bit thinner and get a bit uppity if you stick milk in the coffee” (Russell Lines 416-18). The problem with this is that whilst Russell wanted people to treat him as they did before his ED, his behaviour was totally different than before. The example he gave is perhaps something many people who do not have an ED would consider trivial. A prime reason why people may treat him differently might be they do not want to upset him. On Russell’s part, it is not nice to be the subject of such actions, even if you know they are not intentional. Russell’s behaviour in the previous quotation illustrates to a degree how thinking is affected during an ED.
10.6.2 - THE FAMILY

Russell’s brother lived in a different part of the country and as such did not have a lot of direct or day to day contact with him. Russell said they spoke over the phone and have a good relationship. However, Russell did not say how much support his brother offered him. Russell reiterated (as discussed in Section 10.2) that he has never had a close relationship with his father, partly due to his father’s work commitments. As such Russell spoke of never having connected or being able to share things with him. Of his father’s reaction to his ED, Russell said; “My dad says he fine with it. He listens intently and helps whenever he can and does the whole I’m there for you if you need anything” (Russell Lines 447-48). However, Russell feels that his father does not understand the ED and thinks that Russell should just eat more, and there is also an element of Russell believing his father is ashamed of him. This is extremely difficult to interpret, as a convincing argument could be made focusing on the slight on his masculinity for Russell’s father; having a son with an ED, an illness strongly associated with females. It could also be interpreted that Russell has projected his own feelings onto his father.

Russell spoke of his relationship with his mother as being close, stating that he felt it was this way because he had two near death experiences, one pre-natal and one as a toddler. Her reaction to his ED was extremely positive; “my mum has been very much a case of she will support me in anything I do and will do anything I need and will drop everything” (Russell Lines 442-43). However, this willingness to help her son at all costs has in some ways detracted from him facing up to his ED. For example, the situation when the mental health team were on his doorstep and she came to help (as discussed previously 10.1.3). For a number of years overprotective mothers, and a closeness to them, has been cited in the literature as being a factor in cases of male EDs (Crisp and Toms, 1972; Tong, et al., 2005).

10.6.3 - RUSSELL’S REACTION TO ANOREXIA

Russell’s reaction to his ED was confusing, it was he who initially sought help without the input of his significant others, and it was he who put barriers up to his appointment with the NHS mental health team, asking them to break their routine and not his. Russell, for whatever reason, rejected treatment and then after a period he re-engaged with the health
care profession, this time with a private therapist of his choosing. The overriding attribute which comes from his role in these events is control and perhaps an expectation that people had to fall into place around his wishes. When this did not happen as Russell described, he would get ‘stroppy’ (Russell Line 1057) and ‘aggressive’ (Russell Line 1065 and 1071).

There also appears to be an element of denial in his reaction to his ED, and when talking about how certain behaviours were entrenched in him he blamed his My Fitness Pal App, citing its rigidity. It was Russell, albeit suffering from the ED, who put all the information into the app not the other way around, and he also stated that his brother tried the app and decided that it was not for him. It may be correct that without My Fitness Pal, Russell would not have suffered from the ED, but the behaviours he exhibited, in conjunction with the app, were already there. Denial in Russell’s reaction can also be seen in the statement he made, saying;

   It’s one of these things that always makes it difficult with me in that if you ask me how long have I had my eating disorder I will say four years because it’s four years ago I quit smoking and it’s four years that everything rolls on from, but if you go and speak to my therapist she will say it came out of childhood it only manifested four years ago. (Russell Lines 47-50)

It seems Russell does not accept or cannot comprehend his ED potentially being something which is the manifestation of events, his constructions of them and his coping strategies to alleviate the associated stress. This potential for denial may be due to his masculinity coming to the fore, not admitting to weakness, or is perhaps an unwillingness to look back at previous events and confront his feelings. The final element of denial was discussed in Section 10.3.2. To briefly reiterate, Russell sought solutions for some of the physical and mental effects of his ED in the ingredients of what he was eating, even though his doctor diagnosed a drop-in blood pressure because of lack of food. For Russell, it was perhaps easier to seek blame in an ingredient rather than the actions he was choosing to do and therefore responsible for.
10.7 – ED PORTRAYALS

10.7.1 - THINK EDS ARE A JOKE! I DON’T WANT ANYTHING TO DO WITH YOU

One of the problems with an interview which asks for historical as well as current beliefs and feelings, is that thoughts and feelings may appear conflicted when it is in fact time that has changed the view. This can be seen in the way Russell’s portrayals of EDs have changed. In the previous section (10.6.3), examining Russell’s reaction to the ED, there seemed to be an element of denial, both in terms of symptoms and in seeking help. When talking about his ED in the here and now, the denial shifted and Russell responded as if he has embarked upon a crusade, wearing his ED as a coat of arms on his shield;

I’m very protective of it in that if people use it or anyone uses it in a comedic way I immediately withdraw from them and don’t want anything to do with them .... I also get very angry when people use it flippantly or when they sort of imply that it’s somehow a choice, it makes me angry. (Russell Lines 1177-81)

His decision to withdraw from people who may make light of the ED and his anger at those who think the ED is self-inflicted is interesting. It is perhaps an indicator of Russell still not being comfortable with having the ED or is unable to understand that people may not see things as he does. People may use humour as a defensive mechanism, especially men, and with something such as an ED in a man, as he indicated with the reaction of his friends, people are unsure how to act. The second element of being angry towards people who do not understand EDs and think they are self-inflicted, could be interpreted as being egocentric. For those who are not familiar with EDs, on the surface it is the person with the ED who refuses food, it is they who exercise too much or who purge. People, the general public, do have stereotypical images of people with EDs and because of this may be prone to offend those who have this type of illness. When Russell described his illness by saying “I’m not the 16-year-old [girl] sitting in the corner shaking at the thought of a lettuce leaf,” (Russell Lines 205-06) it could be suggested he is stereotyping, but it also demonstrates how people can easily find offence in what others may say, when it is looked for.

Russell thought that the portrayals he had seen of male anorexia and EDs focused on sports related EDs or the; “masculine chap down the gym desperate for a body, a super body”
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money for Beat. He wanted advice in order to raise money and felt he did not get anything more than generalities, he added; “I know some people who feel exactly the same way” (Russell Lines 1266-67). Russell went on to explain that he asked Beat if he could get a Beat branded running vest for his fund-raising run; “they said just drop us an email and 3 weeks later they sent me a reply back saying if I make a donation they will supply one” (Russell Lines 1269-70). This led to the following damming observations; “I always feel they are actually doing you a favour by talking to you and you don’t feel that supported” (Russell Lines 1271-72). “I’ve always felt with Beat that they are more of a business brand than a charity” (Russell Lines 1279-80). This feeling was reflected in Russell’s experiences of Beat’s website. Russell contrasted Beat with MENGET, where he felt it was clear the people involved, especially the founder, have direct experience of EDs;

> With Beat, there are all just names on a page. You go to their website or whatever and it’s like ‘meet our staff’ and you’re like I don’t know who any of these people are and you always feel like they are just people doing a job because it was a job advertised in a paper (Russell Lines 1288-91).

However, despite being unhappy with Beat it did not stop Russell trying to be active in helping them promote EDs or raise money; “I will bend over backwards to help raise money for them but I just don’t feel quite as connected to them because I don’t trust them as much as I do someone like MENGET” (Russell Lines 1300-02). It is assumed that he means trust in the sense that there is a bond through lived experiences with MENGET, as opposed to anything more sinister.

10.8 – LIVING WITH ANA

Russell spoke candidly about the longitudinal struggles he encountered from seeking treatment, to the day of his participation within this study. Whilst he was planning for a future, going back into full time education, he was concerned about breaking his routines around food; although he had been able to relax them after therapy, they still held great importance in his life;

> I’m a little bit concerned because while I’m eating a lot better now I am still a wee bit shaky about breaking the routine, so I have, my lunchtime is roughly this time, I eat lunch between 1 and 2 most days and I eat dinner at this time at night and I eat breakfast at this time and it’s trying to fit university around that is where the
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that’s a massive amount of calories in one hit, I’m not allowing it’” (Russell Lines 168-70).

### 10.9 – RUSSELL’S ATTITUDE TO ANA

“I don’t like anorexia but there’s this part of me it’s in my head it’s got a bit too much control of me to make me really angry at it either” (Russell Lines 1359-60). Russell was asked for his thoughts about anorexia, his answer showing that even after all of the negative experiences of the illness it still has a hold, because it enables him to be thin and by being thin he is more able to accept his body. Whilst at the time of his interview he stated he was ‘too thin’, he was still having issues with eating. The problem being that he/his brain would not allow him to eat food which would put on weight thereby making him fat again.

Russell stated that he did not like anorexia and he could see how it had negatively affected his life; “there are bits of it now that I can actually think ‘well that’s part of it, something that’s a part of my life that’s come about because of anorexia, that wouldn’t have happened if I hadn’t have had it’” (Russell Lines 1139-41). Whilst saying that he would not wish the illness upon another person, he has used his experiences positively to try and raise money for ED charities. Russell also stated his aim was to dedicate his life to helping people with EDs, which is the motivation for his return to full time education.

However, one element of Russell’s answer to this question stuck out, he said; “I’m not proud of it” (Russell Line 1331). This was unusual wording to use, indicating that he still had not come to terms with the illness, perhaps blaming himself for the illness rather than accepting or understanding that he did not choose to have an ED. This is in direct opposition to his comments previously discussed where he said; “I also get very angry when people use it flippantly or when they sort of imply that [anorexia] it’s somehow a choice, it makes me angry” (Russell Lines 1180-81). It is perhaps more that he was angry with himself and projects those feelings onto others.
10.10 – KEY POINTS FROM RUSSELL’S STORY

- Personal and Background.
  - Parents overweight.
  - Felt closer to his mother, his father’s job entailed a long daily commute.
  - No barriers on food at home.
  - Perfection and Rigidity in personal traits.
  - Became hooked on ‘My Fitness Pal’ a calorie counting phone application.
  - ED behaviours started when giving up smoking in his twenties.
  - In a heterosexual relationship, ED affect his libido.

- ED Manifestation
  - Food restriction in terms of calories but did not stop eating.
  - Exercise.

- Reactions and Treatment Experiences
  - Poor first experience with NHS and then created his own treatment programme using the private sector.

- Work Experiences
  - Stopped working at his main source of income as he was unable to function physically and mentally due to the effects of his ED.

- ED Portrayals and ED Charities
  - Felt portrayals are skewed towards teenage girls, or in men the gaining of muscles.
  - Was unhappy with Beat and felt the charity was corporate and its staff are just employees, unlike MENGET where he felt more of a kinship as the people there appeared to have had EDs.
CHAPTER 11 - RICHARD’S STORY

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons
11.1 – OVERVIEW

Richard was in his mid-twenties and reported a number of incidents in his background story that could be viewed as being traumatic. His first experience of ED behaviour occurred in his late teens when, during his university studies. He found himself hospitalised and in his own words; “almost died” (Appendix 11 - Richard Line 380), due to the effects of his ED on his body’s organs. With his body ‘physically cured’, his narrative tells of his struggles and ultimate rejection by his local NHS trust for specific ED help. From these experiences, Richard has tried to play an active role in trying to spread the word regarding the dangers of EDs in men. This has brought him into contact with ED charities and the media, from which he experienced further frustration.

Within his narrative Richard came across as angry, especially because of his own treatment experiences and those experiences of people he had networked with. Throughout his interview Richard was totally focused on his desire to help others who find themselves in similar situations to himself and was the most forthright participant in the study, giving his opinions and thoughts candidly. However, his ‘confidence’, in his opinion, was perhaps not as strong as his desire to help by participating in the study, and he apologised on a number of occasions during the interview for not answering questions, when in-fact he had, or for, in his words, having a; “rant” (Appendix 11 - Richard Line 313 and 465).

11.2 – RICHARD’S BACKGROUND

11.2.1 - RICHARD’S FAMILY

Richard did not speak in detail about his family background, believing that his ED was not related to; “anything to do with the parental home” (Appendix 11 - Richard Line 139). This could be seen as him being protective of loved ones, but based on what he did share about his background and family, it did feel he genuinely believed that his ED had nothing to do with his childhood experiences. Richard spoke of his mother, father, a brother and sister. At some point in his childhood Richard’s parents divorced and it would appear that he spent time moving between them (discussed in Section 11.2.2).
Richard felt that his issues with weight probably came from the types of foods that he ate growing up due to a lack of family financial resources.

We just come from a really poor family who couldn’t really afford to eat meat. We were living on a shoestring budget and my mum obviously went to the supermarket to get the cheapest which was pre-packaged foods for a pound, where you could get pizzas and things. As a child we grew up thinking it was great. I probably put a lot of weight on because of that (Appendix 11 - Richard Lines 157-61).

When asked about weight and mental health issues in his family, he replied that in terms of weight there were no issues, but his uncle on his mother's side of the family suffered from schizophrenia and his father had suffered from depression. Richard said;

I get annoyed because people automatically pigeon hole people who have anorexia with depression as well. I don’t ever class myself as having depression. I’m too happy a person. Yes, I get my down days, but that’s not depression for me (Appendix 11 - Richard Lines 151-54).

The anger and/or frustration he showed when making this statement was towards health professionals. This was a continuous theme throughout his interview, as Richard felt he was never treated as an individual, but was constantly being forced to fit into a category.

11.2.2 - ENVIRONMENTAL FACTORS IN RICHARD’S WEIGHT LOSS

At his heaviest Richard weighed 22.5 stone. In light of this it is no surprise that around the age of 18, after beginning to put on weight in his very early teens, Richard decided to lose weight. However, his choice of how to lose weight can seemingly be attributed to some of his experiences growing up.

Risk factors within the literature review (Chapter 2) under the section titled ‘Mr Potato Head’ – The John Doe Male Anorexic’ (2.6.2), were clearly evident in Richard’s narrative. Richard spoke of having; “always been funny with food” (Appendix 11 - Richard Line 88) a trait highlighted in Parke et al.’s (2008) case study. Richard stated that at one point he would have to eat crisps with a fork and then wash his face straight after consuming them. This ritualistic behaviour, especially around cleaning, was not only aligned to food, but spread to other areas of his life such as washing; “skirting boards at two o'clock in the morning.” (Appendix 11 - Richard Line 193). ED behaviours often overlap with obsessive compulsive behaviours (Altman and Shankman, 2009), and Richard described his...
behaviour as; “quite OCD” (Appendix 11 - Richard Line 185). Richard also spoke of his perfectionism at school and university, especially where exams where concerned, saying he has; “got to be wired and kept I suppose academically enthused” (Appendix 11 - Richard Line 543). Wired was a term used by Richard to describe a desire to learn new things or perfecting existing skills.

Isolation was a problem for Richard before his ED. This was in part due to a nomadic existence, where he never lived in the same place for longer than four years. Because of this he had to move schools a number of times and was not able to establish friendships. Richard spoke of one such move in his teenage years where he moved from an area he liked to another area; “I had no friends and I was at a completely new high school and it was difficult to settle in so the weight piled on. I used to isolate myself at home. I was bullied at school as well” (Appendix 11 - Richard Lines 175-77). Richard’s nomadic lifestyle was not helped by his parents divorcing and what appears to be a lack of stability was echoed when he said; “I’ve always moved from mum’s or my dad’s place” (Appendix 11 - Richard Line 174). However, Richard did not elaborate why this was the case, and could have been due to Richard wanting to be with different people at different times, financial circumstances or he could have been the subject of a tug of war on the part of his parents.

Richard felt that his upbringing and the upheaval he experienced meant; “I was a little more mature than the children of the age I was, because I had to grow up a lot quicker because of the family situation we had” (Appendix 11 - Richard Lines 358-59). This maturity hindered his ability to fit in, resulting in his observation;

I was the silent figure, the one that could never relax and [having to] follow the rules. As a child growing up, not all children are like that and I was always organized. I did have a friend or a cluster of friends, but it was never the friendships you see everybody has or what you think they have. (Appendix 11 - Richard Lines 359-62)

Tellingly, Richard finished the comment with ‘what you think they have’, this enigmatic comment can have many different meanings, but it is easy to interpret that even at an early age he was looking at others and comparing himself to them.

Richard was gay, which Russell and Keel, (2002) identified as a risk factor for EDs. However, Richard stated that this had never really worried him; “because I came from a
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comment therefore that the abusive events could have something to do with his ED experiences would appear to be fully justified.

11.3 – RICHARD’S ED

11.3.1 - RICHARD’S EATING DISORDER GOAL

Richard’s body image concerns, due to his size, were the driving factor in the decision he took to lose weight. He stated that his goal was not to look muscular, but to; “look thinner and for me that thin skeletal male look is normal. Whenever I say I want to feel normal that’s what I want to look like, I don’t want to look like a big action-man” (Appendix 11 - Richard Lines 115-17). Richard’s desire to be thin as opposed to more muscular is in contrast to what is espoused in the literature (Dissing et al., 2011; Strother et al., 2012). However, Richard’s homosexuality needs to be considered in this particular context.

Richard, whilst agreeing of their existence, rejected the sex roles of gay culture described by the other gay/bisexual men within this study. Richard’s desire for thinness though was aligned with other research findings suggesting in order to attract a partner, gay men strive for thinness (Brown and Keel 2012 and 2014). Even though he rejected the sex roles and took no part in the culture he still aspired to them.

11.3.2 - TAKING A ‘FRIEND’S’ ADVICE

When Richard decided in his late teens that he wanted to lose weight a friend recommended some websites for him to look at. Richard acted upon the advice and soon found himself losing weight. The problem with this he believed was; “little did I know at that time that they were thinspiration websites and full of internet trolls …. they were encouraging really extreme diets.” (Appendix 11 - Richard Lines 51-53).

Richard’s experience of thinspiration websites is a bleak account, whereby he felt under increasing pressure to cut foods out of his diet. At first, he found his weight loss; “quite euphoric and was seeing results quite quickly and I thought this is quite good” (Appendix 11 - Richard Lines 81-2). However, he found that there was no way of pleasing his ‘friends’ on the websites;
I thought that people in the on-line chat rooms were genuine friends at the time, but then they started getting nasty. The more weight I lost it wasn’t good enough for them and they wanted more and they wanted double and they wanted it quicker and they were egging me on. (Appendix 11 - Richard Lines 82-85)

Richard spoke about wanting to lose weight so much he lost control and his life was taken over by his ED;

I was so desperate to lose the weight that I did it and eventually I had no control over what I was actually doing. I didn’t realise at the time the disorder had taken over control of me. I lost control of the whole dieting and everything and it became an eating disorder. (Appendix 11 - Richard Lines 85-88).

His loss of control is illustrated by his acquiescence to a request from members of the site for him to take carbohydrates out of his diet which was then followed by a request for him to exist on nothing but sugary tea. This last request saw him lose a huge amount of weight and ultimately be hospitalised with serious damage to his gall bladder and pancreas.

Richard said that the websites promoted a skeletal male physique, reinforcing this with images; “of young boys and young adolescent males with their hip-bones sticking out, their rib bones” (Appendix 11 - Richard Lines 103-04). He also added that slogans were used such as “eating is cheating” (Appendix 11 - Richard Line 104), and graphics would change the letter ‘e’ in the word eat to an ‘f’ spelling fat. The question not asked was why he engaged in this behaviour in the first place, when he initially went on such sites, before his ED, he would have seen the images and captions. Perhaps the answer is simply that he; “was so desperate to lose the weight” (Appendix 11 - Richard Line 85), his mind was ignoring any danger signals or perhaps there was cognitive dissonance.

Richard shared that he; “started bullying people” (Appendix 11 - Richard Line 92) on the websites and forums as in his words; “the disorder had taken over control of me. [Inaudible comment] I didn’t have any control over what I was doing, but I did feel euphoric” (Appendix 11 - Richard Lines 92-94). His behaviour in this instance showed signs of aggression, but also shows how the “positive aspects” of his ED (weight loss, confidence) can become all consuming.
11.3.3 - FROM THINSPIRATION TO OUT OF CONTROL - ED MANIFESTATION

From trying to lose weight by using what transpired to be thinspiration websites Richard stated that he; “lost control of the whole dieting and everything” (Appendix 11 - Richard Line 87). Richard’s ED manifested itself in a number of different behaviours. As stated in the previous section he restricted his diet to such an extent that he survived for a period on sugary tea. He also engaged upon what can be described as an excessive exercise regime which he exemplified by saying; “Throughout my time at university I was exercising every single morning before lectures; 6am in the morning until my lectures started. I wasn’t eating and then I’d come home and do the same again” (Appendix 11 - Richard Lines 57-60). Richard also purged himself by vomiting and using laxatives.

Richard said about his behaviours, specifically his purging; “It became part of my routine really, I didn’t actually think anything of it. I just thought... I hate to use the word normal, but it became normal for me. It was part of my life and part of my identity” (Appendix 11 - Richard Lines 415-17). Normalising the behaviour could have had a beneficial role as it helped him to lose weight, perhaps indicating the control an ED has over a person. On vomiting Richard said;

I hate being sick and I actually feel ill, but nobody likes being sick, let’s face it, but to actually have to do it because of your disorder, it again became routine. In the initial stages it was horrible, but the disorder was egging me on; it gave me that euphoric feeling. (Appendix 11 - Richard Lines 433-36)

Richard found that vomiting allowed him to purge whilst being able to maintain a façade of normal life. Richard explained people got suspicious if he did not eat when in company;

If you eat people think you’re normal. It’s almost trying to be socially normal to be normal to eat with them so I felt pressured to eat with them. I would eat with them, but I could throw up without feeling guilty about eating it…. and still maintain that normal identity that I had. (Appendix 11 - Richard Lines 437-39)

Richard’s weight loss allowed him to create a new identity based on having the ‘right’ body image and he became more confident, using his ED behaviours to reinforce his new status; “the disorder made me feel if I was eating it would take that identity away from me and the old one would come back, the old me would come back, people would stop talking [to me]” (Appendix 11 - Richard Lines 440-41).

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On his use of laxatives, he said; “it was almost like getting the poison out of my body” (Appendix 11 - Richard Line 450). The use of the word poison in reference to food is telling, as whilst we need food to fuel ourselves, Richard saw this as something that would harm him. An important distinction needs to be made which Richard felt was important to stress; it was not food which was a problem, but the calories that were an anathema to him.

“I was craving the taste of food, that’s what people don’t understand, being anorexic. I love food, I want to be around food, I prepare food all the time, but I wanted to taste it, I wanted to taste it without having to put the calories on” (Appendix 11 - Richard Lines 454-56). Richard said of his purging, “It made me feel happy in terms of keeping the euphoric feeling to flush that out and be able to eat it” (Appendix 11 - Richard Lines 453-54).

Purging allowed him to live his new lifestyle which had opened up with his weight loss; “I could still have this glamorous lifestyle almost, I use the word glamorous because that’s how it makes you feel like, on top of the world and you can get rid of the poison you are putting in there” (Appendix 11 - Richard Lines 457-59).

Richard’s desire to fit into his new lifestyle saw him eating to ‘fit in’, or as he suggested; “eating it just to make them happy” (Appendix 11 - Richard Lines 450-51). However, this pleasing of others he also recognised as not being a trait he suddenly found when he was dieting; “I think it’s fascinating looking back at, to talk about it, it’s always trying to make other people happy. Even when I was larger everything I was doing was to make other people happy so I could be normal and fit in with them.” (Appendix 11 - Richard Lines 451-53).

11.3.4 - REBIRTH: THE BENEFITS OF AN ED

A section with ‘benefits of an ED’ in the title may seem ludicrous, however it must be conceded that changes in Richard’s life whilst experiencing his ED were seen by him as beneficial, enabling him to carry on with his behaviours. When Richard started to lose weight, he stated that he felt like a new person, people started speaking to and taking notice of him. He said “these things that I had because of the eating disorder felt like a new identity, a new person” (Appendix 11 - Richard Lines 419-20) He decided to change his surname from his father’s name, adopting his mother’s; gone was the; “old fat Richard that existed, the one that people hated and bullied.” (Appendix 11 - Richard Line 420-21), and
he was replaced with; “the new adult good Richard” (Appendix 11 - Richard Line 421). His name change signified a rebirth and the abandonment of his father’s name, perhaps indicating a poor relationship with his father and a break with the side of the family of the person who raped him.

With his weight loss Richard found confidence to step outside of his comfort zone; “I was doing lots of things…. I would never have done before” (Appendix 11 - Richard Line 493). This included drinking and experimenting with marijuana at university, as well as volunteering for lots of different activities. Richard said; “I felt like to keep this thing going I had to keep busy and be out there and be proactive” (Appendix 11 - Richard Lines 520-21). He continued “my behaviour changed lots. I went from being this person who stayed in the house all the time to being this extrovert person and doing absolutely everything that I’d never done before” (Appendix 11 - Richard Lines 521-24). On reflection and with the benefit of hindsight, Richard felt that his confidence was more to do with people pleasing and;

To make people think I was a great thing, to keep this façade, this identity up that had been created by an eating disorder, although the part of it was me itself, it wasn’t actually who I was. It was painting multiple characters, who I was depending on, the people and the social ……that I hung around with at that time. It was almost like putting a different face on for them. (Appendix 11 - Richard Lines 529-33.

The interpretation from this comment being that he had to keep the façade up, which meant losing more weight. If he stopped being busy, he would stop being popular and go back to the pre-ED Richard.

Another benefit of his ED was that Richard found he had a heightened sex drive, this, although seemingly at odds with research, (Keys, 1950; Freedman 2005; Lindblad 2006; Agalusca et al., 2012), was also reported by the other gay man in this study. Richard said;

I had a much higher sex drive, being anorexic gives you the euphoric feeling, God knows where I was getting the energy from, but it gives you this ADHD energy, you know, where you’re bouncing from the walls. In terms of the libido itself I had a high sex drive. (Appendix 11 - Richard Lines 466-69).

It would seem that as Richard lost weight and his confidence increased he became more attractive. While rejecting gay community stereotypes around sex roles, Richard’s desire to be as thin as possible did fit into the ‘social expectation’ for a gay man of his age.
Likewise, his promiscuity of which he said; “It makes you feel more; you love yourself much more. When you go out you seek it because you’re [inaudible] you can do anything basically or any, anybody basically” (Appendix 11 - Richard Lines 714-16). Richard did report that as his ED continued his energy levels dropped, which although his sex drive may have remained to an extent, his ability to engage in sexual activity may have been compromised and could be considered in keeping with previous research (Keys, 1950; Freedman 2005; Lindblad 2006; Agalusca et al., 2012).

11.3.5 - ANOREXIA: NOT ALL GOOD NEWS

Richard experienced a number of issues both physically and mentally which stem from his ED experiences, some of which he was still living with at the time of interview. Due to using vomiting as a method of purging, Richard stated that he had ongoing problems with his teeth. Despite his euphoria over his weight loss when he was experiencing his ED, he stated that; “there’s not a minute goes by I don’t feel conscious about how I look” (Appendix 11 - Richard Line 905). Richard felt that because of his ED he was more controlling as a person and more impulsive than he was pre-ED. As discussed in Section 11.3.4, Richard felt his ED was in some ways responsible for his drinking and drug taking at university. Richard spoke of a need to control things in his life which he said; “I have to make itineraries for everything.... it’s got to be almost, be regimented in everything” (Appendix 11 - Richard Line 479-81).

Richard also noted that he became more aggressive with people. He would become irritated much more quickly and would isolate himself from them by not speaking to them. He said about people and food; “what they were doing with food and things was not what I thought were acceptable. I would have a big go at them and bring them down for it” (Appendix 11 - Richard Lines 510-11). Richard was not clear in the previous example if he was referring to his role as bully on thinspiration sites, or if this related to people in general and their views about food. However, he was clear that his aggression or shortness was directed at anyone who fell short of his ideals (perfectionist tendencies); “if they [people] didn’t turn up to university at a certain time I would disregard them, I would snap” (Appendix 11 - Richard Line 511-12). Richard also commented that he found it very difficult to relax, perhaps an outcome of his turbulent childhood or equally it could be a
sign of his under nutrition or ‘depression’. Richard stated; “I was spinning 90 plates at once” (Appendix 11 - Richard Line 519), a metaphorical allusion to his need to be constantly doing things. As a result of this, and it is assumed his new lifestyle, Richard found his sleeping patterns changing and he became more nocturnal. From Richard’s narrative, it appeared that he had always found relaxing difficult and had a need to be ‘doing something’. He believed this need increased during the ED; “if anything this disorder has made me more wired than ever before. Like I have to be constantly stimulated, I have to be doing something” (Appendix 11 - Richard Lines 540-42).

However, this comment needs to be treated with caution. Firstly, Perron et al. (2015) found that initial weight loss and a healthier diet would lead to a period of alertness. This is what Richard may be referring to when he described his increased popularity at this point in his life, and coincidentally having more desire to do things regardless of his energy level. However, later in his narrative Richard commented about acute tiredness and the loss of time when at university, where he had episodes of not knowing the day of the week.

When asked about the ED and the impact upon decision making Richard said; “I’ve never been tired or found it hard to make decisions. I suppose when the disorder was at its worst decisions weren’t actually mine and I remember it being a big blur” (Appendix 11 - Richard Lines 544-46). This reference to decisions not being his refers to his treatment where he found himself hospitalised and not being in control of making his own decisions which is examined in the following Section 11.4.1. Richard’s comment about never being tired was surprising and it led to me questioning his ability to function both at university and at work. Richard responded by saying that when he was; “really thin, I’d find myself sleeping, after I came home from university. I couldn’t physically get the energy to move, I’d just sleep all night” (Appendix 11 - Richard Line 522-23). He continued and said that he missed a number of days at university because of his tiredness, which got him into trouble;

I remember waking up one day thinking it was Wednesday and it was actually Saturday or something and then getting an email from the university to come in for a student disciplinary because I’d missed my lectures and stuff. It was almost like I’d blinked my eyes for a second to it and woke up to it again. I didn’t feel like I’d slept, apparently, I slept for days on end. (Appendix 11 - Richard Lines 554-58).
The inconsistencies in Richard’s narrative regarding tiredness could be attributed to selective memory; being more inclined to remember the positive aspects of his ED, and only when prompted he was forced to consider the more negative aspects and how it impacted on his life. However, it should be noted Richard’s journey from being obese to being hospitalised for low body weight, was lived out over approximately two years, and for a period of that time, with his weight dropping, he would have probably felt good (from a physical view to get from obese to underweight must have included a period within the healthy weight range). However, it got to a point where he lost days due to sleep and as he reflected; “I hardly had the energy. At its worse that’s what it was like” (Appendix 11 - Richard Lines 559-60). However, it got much worse for him than just sleeping a lot.

11.4 – TREATMENT AND CARE (OR A LACK OF IT)

11.4.1 - PUKing, Peeing Blood and Seeing Red With the NHS

Richard collapsed in his room at university after approximately two years of his diet/ED behaviours and after losing approximately 70% of his body weight. Before he collapsed into unconsciousness Richard remembered vomiting blood and passing it in his urine. Upon waking he found himself in hospital having been diagnosed with gall bladder and pancreatic problems, as well as anorexia. This was the first time that Richard had ever thought about anorexia.

Richard found his treatment of these problems to be frustrating, causing him to reflect angrily about this particular experience. He said that his doctors were; “more interested in sorting the pancreas and the gall bladder problems than the eating disorder” (Appendix 11 - Richard Lines 238-39). This on the face of it seems a disingenuous comment as his care team’s primary role would have been to treat his most life-threatening ailments first. However, later in his narrative Richard stated;

They kept me in there for months, in the dark, I remember getting frustrated and looking it up on-line myself, male eating disorders, and I found the Men Get Eating Disorders Too Charity. (Appendix 11 - Richard Lines 248-50)
During his time in the hospital it appeared that Richard was not referred to or saw an ED specialist. Richard said;

They weren’t interested in fixing the mental health and the eating disorder, because I feel for them as doctors, what they knew best was how to fix the physical. Rather than refer me to a dietician, none of that was done. (Appendix 11 - Richard Lines 246-48).

This led to Richard self-referring to his local mental health/ED services, but stating he was refused treatment at that time because of his gender; “I was refused because I was a male and they had lots of females coming through. There was such a shortage of beds, despite the fact I was classed as nearly dead” (Appendix 11 - Richard Lines 252-53). He went on to say;

There were more females coming forward for eating disorders. As a result, they had very limited spaces of beds and as a result because I was male I would have to wait longer and that was a telephone call when I phoned up to chase up about the self-referral. I’d had enough about getting into hospital, finding out about this disorder through research and thinking ‘I could die from this thing, I want to get help for it’ and then I self-referred myself and then to have the door closed on me because of the bias of the gender, it’s ridiculous (Appendix 11 - Richard Lines 262-67).

In light of the above it seems inexplicable that Richard, who had been admitted to hospital because of complications due to his anorexia, could not get specialist ED treatment. At his lowest weight, his BMI was well below the threshold for anorexia, the point at which it would be expected someone would receive treatment. Although conjecture, it is perhaps the most feasible explanation that whilst in hospital Richard put on enough weight to move him out of the ‘at risk’ levels on BMI scales, thereby putting him back down the waiting list when he referred himself. Although the question as to why he was not initially referred to specialist ED services when diagnosed remains unanswered. Richard at the time of his interview was upset and angry at his treatment suggesting;

When I was at my worse they had the duty of care to help me and they failed that duty of care because of the fact I was a male and the health board have denied that claim to this day, which they will do because they’re trying to cover their own back (Appendix 11 - Richard Lines 333-36).

Richard went on to say; “I’m furious, I’m still furious to this day about it” (Appendix 11 - Richard Line 289).
11.4.2 - NHS REJECTION LEADS TO DIY TREATMENT

“So, without NHS support or parental support, any sort of support at all to get through this eating disorder.” (Appendix 11 - Richard Lines 280-81), Richard found himself having to use his own methods to deal with and overcome his ED. Some of the strategies he used were perhaps not the most helpful for long term benefit. His narrative suggested that the main thrust of his strategies were still about people pleasing; “I was doing xxxxxx teaching and I wanted to get better for my pupils and for myself and my degree teacher at university” (Appendix 11 - Richard Lines 281-82). Although he mentioned himself, this was sandwiched between two other parties his pupils and his teacher. This in itself was interesting as it could be construed that if he were not able to teach his pupils he would have been letting them down, which falls into the ‘people pleasing’ traits of EDs. However, it could also be argued that this is a similar sentiment which some of the other men interviewed talked about when discussing the importance of their loved ones in helping them. Apart from the help he received from his degree teacher who, Richard stated; “got me through it just by being there” (Appendix 11 - Richard Lines 282-83). Richard’s psychological help amounted to a couple of counselling sessions whilst at university. However, he also added; “I didn’t think counselling was for me. I’ve felt I could have sat and talked to a brick wall about this stuff. I don’t feel it helps me at all.” (Appendix 11 - Richard Lines 328-30).

11.4.3 - OPINIONS OF THE ‘PROFESSIONALS’

It was perhaps no surprise, given his experiences, that Richard did not have the greatest regard for the medical profession or researchers. He candidly said;

Professionals say ‘I know about it’, well you don’t know about it, you don’t know what it feels like, you’re not living this thing all the time. You’ve read it in a book; any numpty can read it in a book. (Appendix 11 - Richard Lines 336-38)

His words reflect a desire for empathy and understanding for his experiences, which he felt he had not experienced. He also stated that a one cap fits all approach to health care did not suit him;

I get annoyed when I read a lot of this research out there from these ‘professionals’ because they’ve read so much in their books that they believe all
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men want to look that way and all women want to look thin, it’s not that way at all, not for me anyway. (Appendix 11 - Richard Lines 150-53)

Richard’s words indicated a level of frustration and anger with his treatment experiences, yet there was perhaps an element of denial or inability to come to terms with his ED. However, research is based around evidence and sometimes findings when used as a blanket do not fit each individual completely.

11.5 – REACTIONS TO ANOREXIA

11.5.1 - RICHARD’S REACTION

Although Richard was aware that his life was deteriorating, engaging in the thinspiration sites, at the time he described himself as being; “frightened” (Appendix 11 - Richard Line 94), he did not know what help was available, stating; “I thought especially being a guy, I thought it was maybe just a phase I was going through or something” (Appendix 11 - Richard Lines 95-96). This in itself illustrates some of the issues which surround men’s health and well-being, with men being reluctant to come forward and seek help due to stigma and/or ignorance (Cooperman, 2000; Duker and Slade, 2003; Paterson, 2004; Soban, 2006).

Richard said that when he was diagnosed with anorexia it was the first time that the ED had crossed his mind. He said; “I never knew anything about it other than it being a girl’s thing. It never even crossed my mind a guy could get it” (Appendix 11 - Richard Lines 437-38). Anorexia, Richard said, was something that he had no experience of, saying that his only references to EDs were Karen Carpenter and a character from the soap opera Hollyoaks; “I’ve never known a guy that has had an eating disorder. I didn’t even know what it was” (Appendix 11 - Richard Lines 210-11). With Richard’s own “blissful ignorance” (Appendix 11 - Richard Lines 349) as a frame of reference, perhaps his family’s reaction (11.5.3) was more understandable. Richard said; “I never thought for a minute I had anorexia” (Appendix 11 - Richard Lines 350-51).
11.5.2 - FRIEND OR FRIENDS?

Richard said that his peers at university finding out about his ED; “were quite shocked. My friend at university, well my classmates had noticed the weight loss and they did comment on it just before I went into hospital” (Appendix 11 - Richard Lines 370-71). Richard’s use of the term ‘friend’ is interesting as this is singular, he then paused and said; “well my classmates”; this can be construed as him being isolated at that time, with few or no friends, only acquaintances.

Richard felt that if someone had said something to him early enough it may have changed what happened to him;

I know it’s quite a sensitive issue, had somebody a month or two months earlier said something, ‘maybe I think you’ve got this’ or ‘maybe you should see a doctor, I’ll come with you’. Maybe just pledged that little bit of support in the initial stages that would have save me going into hospital and I wouldn’t have got to that stage where I almost died (Appendix 11 - Richard Lines 376-80).

Whilst his sentiment was understandable, speaking when reflecting on his experiences, his ability to listen to, the voice of ‘another’ at that time would be questionable. Furthermore, his lack of close friendships may contribute to why no one challenged him regarding his ED problems.

Although the reaction from his peers was shock, one person was different;

There was a friend at the time who told me it was self-inflicted and all my own fault and I actually believed that for a while. I thought that’s what it was maybe it was all my fault. Initially I’d chose to lose weight and that’s what had happened (Appendix 11 - Richard Lines 380-83).

Richard eventually was able to realise that his ED was not self-inflicted, but his friend’s behaviour was not an isolated incident;

There’s quite a lot of people, including my brother, who said it was all self-inflicted. To this day my brother still thinks it’s self-inflicted, he can’t get the idea that it is a control thing and I have no control over it sometimes. It comes and it manifests I suppose but... a lot of them felt the fact that it was self-inflicted (Appendix 11 - Richard Lines 384-88).

This quotation shows how there is a need for people to be educated around EDs. With the levels of stigma associated with male mental health, and EDs in particular, it is a safe
assumption that it is not just Richard who has experienced loved ones and friends labelling an ED as self-inflicted.

11.5.3 - THE FAMILY REACTION

Richard’s family’s reaction, as told in his narrative, was not encouraging, and it would seem that his brother’s belief that the ED was self-inflicted and his lack of understanding was shared partially or wholly by others. The only member of his family who he reported as showing concern was his sister, who he described as being worried. This is not to say that others were not worried or upset or unsupportive, however he did not report them being so within his narrative. Richard’s sister tried to help him by getting him to put on weight, which as Richard said; “didn’t fix the problem” (Appendix 11 - Richard Line 394).

According to Richard other members of his family believed that he was not eating by choice and thereby could simply fix the problem himself, whereby others thought he was merely attention seeking. The conclusions that can be drawn from this section of Richard’s narrative is that his family did not have any understanding of his ED. Richard felt this was in part due to the stigma of the ED; “it’s the stigma thing and the worst part of it I think, because people have preconceived ideas of what it actually is. They can’t see it through your eyes, they don’t have it. It’s quite hard for them to comprehend what it is, including the professionals” (Appendix 11 - Richard Lines 396-99).

11.5.4 - LIFE AT WORK; CANCERS OK, EDS NO WAY!

Richard spoke of the reaction he had at work from his bosses; “I found work wasn’t really supportive because they just see it, as again it is a stigma thing, all in my head, self-inflicted, get back to work blah blah blah…. then you know you’ll be fired” (Appendix 11 - Richard Lines 739-41). Richard felt that if he had suffered from Cancer his employer would have been more supportive, believing that because it is a physical illness they could have understood it better. As with his family’s reaction in the previous section, Richard believed stigma was a significant barrier and people with mental health issues should be better protected by the equalities legislation;

Unless they’ve had an eating disorder or a mental health condition it’s quite hard for an employer [inaudible]. I think they need a legislation put in place to protect the employee at work who has a mental health problem and protect that
characteristic when it come the equalities act in my opinion (Appendix 11 - Richard Lines 744-47).

Richard complained that although it is recommended to eat three meals a day it is not law, believing people knew he had an ED and because of this watched him to make sure he ate his meals;

Who says you should eat three meals a day? It’s only government recommendations. It’s not a law that says you miss a meal out of the three meals that day and it is the end of the world. But the minute someone knows you’ve had an eating disorder, you miss one of those three meals, particularly at work they notice that. (Appendix 11 - Richard Lines 734-38).

Richard thought this was particularly the case at work, although he did not specify if this was his colleagues or his managers who did this. However, the way in which Richard spoke of this subject indicates that it was not something he was happy with.

11.6 – GENDER INEQUALITY, STEREOTYPING AND GAY ‘CULTURE’

Gender stereotyping and inequality are a sub theme within Richard’s narrative, the story of his NHS treatment rejection was examined in Section 11.4, however, his thoughts on this subject are worthy of a full independent section.

11.6.1 - GENDER INEQUALITY

Richard said on the subject; “if you look at the literature, the literature is the biggest part of the stigma in my opinion” (Appendix 11 - Richard Lines 307-08). Richard believed the literature he received from the NHS was written in such a way it excluded males. He identified the language such as; “when the girl has anorexia, the girl, the female, the woman, they talk about the ovaries and things stopping” (Appendix 11 - Richard Lines 308-09). He also suggested that the design and colour choices of such written information added to the misinformation, as such Richard felt it should not be a surprise that men do not seek medical help if things are tailored towards females;

There’s talk about barriers when it comes to eating disorders, but I don’t think they ever touch the surface. In my opinion, the biggest barrier is the health care profession handing out a leaflet about eating disorders, and it’s a very female gender biased to the female gender. The way it’s written, the colour of that. All the
things they don’t bother taking into consideration that will put a guy off from even touching it. (Appendix 11 - Richard Lines 322-26)

Richard’s advice to the NHS regarding men’s ED’s was; “don’t just sit back and wait for them to come to you, what are you doing to get them to come to you? That’s what you should be doing as a health board. The NHS is a people’s service” (Appendix 11 - Richard Lines 330-32).

Richard believed this inequality was not just restricted to the NHS, but to U.K. society in general. He believed there is a pro-feminist drive, but no; “equal rights when it comes to males, masculinity and men in general” (Appendix 11 - Richard Line 626). He highlighted that the debate on body image, and the irony that no one seems to take offence that young male children are sold super hero costumes, emphasising the male ‘six-pack’, yet if the opposite sex was sold; “costumes of princesses, with their boobs hanging out of them or a high skirt with a pair of high heels, and aimed that at young five-year-old girls, there would be uproar” (Appendix 11 - Richard Lines 628-29). It is these double standards starting at an early age, Richard believed which puts pressure onto boys about their appearance and masculinity, whereas in females it is accepted that this should not be the case. Tellingly Richard said; “we are all looking for women’s rights, but we forget about men” (Appendix 11 - Richard Line 678). Richard felt only certain male body shapes or male attitudes were accepted; “it’s ok to drink 10 pints of lager, the lager belly and that’s what being a man is, speaking to people like rubbish, the shaved head type thing” (Appendix 11 - Richard Lines 667-68), or the image of the big strong man with muscles and a six pack that is promoted. He said;

It’s never ok to be a thin, young man; you’re seen as puny and you’re laughed at. You look like a boy even at aged thirty. But it’s ok, we celebrate women’s body types of all types and sizes, but what about men, we don’t do anything about that. That’s where we have a problem with masculinity I think. (Appendix 11 - Richard Lines 671-74).

11.6.2 - MASCULINITY

Richard had strong views of his masculinity saying; “I’m of the belief I’m very masculine, I feel myself very manly and I don’t like the fact that professionals try to portray it [anorexia] as a very feminine thing, a very feminine/gay man thing” (Appendix 11 - Richard Lines 608-09). Richard’s rejection of the medical profession’s views is
understandable, especially if a man does not want to feel marginalised. However, research has indicated that femininity is a risk factor in EDs (Murnen and Smolak, 1997), and statistically gay men are at a higher risk than straight men (Brown and Keel, 2012). Regarding the above there is no statistical evidence of men or women who do not engage with health services, so the actual figures could be much different (Hudson et al., 2007).

What may be surprising for some about Richard’s view of his masculinity being feminised, through anorexic stereotypes, is his own sexuality. Being gay there is a stereotypical assumption that Richard is already feminised. For example, he cannot fit into Connell’s (1995) Hegemonic Masculinity and, on the basis of his sexual desires directed away from females (and reproduction), there can be no question of him ever achieving hegemonic status. However, Richard has in many ways rejected traditional views of masculinity saying it; “means nothing nowadays, it’s all changed” (Appendix 11 - Richard Line 601) and has created his own form of masculinity. Richard’s rejection of ‘traditional’ views of masculinity was shown most vividly when he said; “I don’t like football either, but it doesn’t mean I’m any less of a man because I don’t like it” (Appendix 11 - Richard Line 661). This is interesting as it is a sport in which a number of the men interviewed seem to use as some kind of barometer of manliness.

Richard said; “I identify as a man, I like shaving and stuff, it sounds stupid to me. I identify as masculine because I am a man. I like the muscular physique a man has; the body thing is to me what being a man is” (Appendix 11 - Richard Lines 655-57). This in itself was an interesting comment, as his own goal for losing weight was; “I’ve always wanted to look thinner and for me to look that thin, skeletal male look is normal” (Appendix 11 - Richard Line 115). These two positions regarding the male body appear conflicted; while Richard strongly identifies with being a man, that is a person who has a muscular physique, he also strives to achieve skeletal thinness. One interpretation of this could allude to Richard’s taste in a partner, alternatively it could indicate confusion around his own body image.

11.6.3 - GAY SEXUAL ROLE STEREOTYPING

Richard rejected the use of the term gay community when being asked about sexual stereotypes. He felt the use of the word community was wrong; “A community if you look...
at the wording is a group of people that accepts lots of other people. I view the scene, and not the community, as being very exclusive and very cliquey, you fit into it” (Appendix 11 - Richard Lines 698-700). His wording was interesting indicating that he viewed the gay scene as something which people have to mould themselves to in order for them to fit into it, adopting inflexible roles. “I think the more you seek that community the more you become involved in it and you follow that clique” (Appendix 11 - Richard Lines 705-06), these were Richard’s words when describing his avoidance of the ‘scene’ and the stereotypes within it. What was interesting was that his rejection of this grouping further marginalised him.

Richard did agree that for those who engaged with the gay scene there was a sexual hierarchy and sex roles; “you fit into the slim feminine gay man, you fit into the butch, fat type of guy or the lean muscular one” (Appendix 11 - Richard Lines 700-02). Although Richard said he did not take part in the scene, it was interesting to note that his desire when setting out on his weight loss was to be as thin as possible. This could be seen as being remarkably close to the slim feminine role he described above and the conclusions of Brown and Keele (2015) who noted objectification theory with gay and bisexual communities.

### 11.7 – CHARITY BEGINS, AND ENDS, AT THEIR HOME

Richard spoke candidly about his views of the ED charities, living in an area of the country well away from the South East where Beat and MENGET have a better reach. In doing so he was quite scathing and took steps himself to help others.

#### 11.7.1 - BEAT “THE MONEY WHORE”

In 2010, when Richard was first diagnosed with anorexia he used the internet as a tool to gather information and came across Beat’s website. He said; “I didn’t feel it was right for me. When I looked at the website and it was women hugging women, pink colours, it wasn’t right for me. I was wanting information about why a guy has it” (Appendix 11 - Richard Lines 752755-32). Considering Richard’s views of gender inequality for men with anorexia it was no surprise that he sought engagement with MENGET, as this is a male
specific site. However, despite personally using MENGET’s forum, because of his voluntary work Richard has engaged with Beat repeatedly and he said about the charity;

   Beat, I feel is a money whore as a charity and I use that phrase quite big, because they are more interested in chasing the money and do very little work across the United Kingdom, despite the fact they are registered in all parts of the United Kingdom (Appendix 11 - Richard Line 761-63).

The term ‘money whore’ was a very strong statement. Richard’s point was that for a national charity it was not national, as people living in his part of the country could only access live help via a chat line one day a week. He felt that the charity’s work was not national and did not justify the media coverage it received or the promotional activities they embarked upon. Richard stated; “if they are going to be the [national] eating disorders charity they need to step up to that mark, considering all the money it gets and the media coverage [quoted in the press when ED stories are discussed]” (Appendix 11 - Richard Lines 820-21). Richard was disparaging of Beat and questioned the accuracy of the information they present;

   The information they’ve got, the media guidelines they have, out of date, wrong information on them, the statistics are biased, it’s not good enough. I’ve been on to the charity several times about all that. I’ve watched them on the news as well and again they are always biased towards females. I’m sick of it and all of the statistics [are not about] males. (Appendix 11 - Richard Lines 822-26)

Although seemingly controversial, Richard’s comment shows a desire or need to help people with EDs, and with a background in charity work his comments should not be dismissed outright without scrutiny.

11.7.2 - MENGET – IT’S NOT ALL ABOUT YOU!

Although Richard posted on MENGET’s forum over a number of years, and as with his experiences of Beat, his voluntary work gave him a view of the organisation which led to him concluding that too much emphasis was placed on the charity’s founder; “a lot of work is being sourced to xxxxxxx [founder], it’s very xxxxxx [founder]. That’s not what the charity should be about” (Appendix 11 - Richard Lines 780-81). He also criticised MENGET’s geographical reach, despite being a national charity their reach is very much in the south of England; “they get a lot of money so they spend the money in the one area of England” (Appendix 11 - Richard Line 783).
Speaking about his voluntary work, Richard described the poor relations he has experienced between the two charities. Richard stated there is; “a lot of conflict going on there” (Appendix 11 - Richard Line 791). He clarified this statement by explaining it was difficult to avoid being dragged into it, and felt it hampered the work of helping people with EDs; “I can’t be bothered with that and a lot of the organization’s people can’t be bothered with that, you come in to help people, not get involved with politics.” (Appendix 11 - Richard Lines 793-94)

11.7.3 - WORKING WITH THE DEVIL

11.7.3.1 - Media Portrayals of Male Anorexia

Richard had direct experience of media portrayals of males diagnosed with anorexia, having tried to raise awareness by speaking about his own experiences. He had also attended conferences and reported a BBC employee, who when speaking to him and a group of people, stated; “‘she’s not interested about the person in the story’, that was her words. Safe to say there’s quite a few angry people in the xxxxxxxx conference that day, including myself, when she said that” (Appendix 11 - Richard Lines 838-40). Richard believed that whilst a journalist has a job to do and a story to tell to their audience, there should be an awareness of their responsibilities to the subject of their story; “these aren’t celebrities you’re trying to glamorise, these are normal people going about their daily lives that have told their stories” (Appendix 11 - Richard Lines 842-43). Richard made a valid point that people who in this case tell their stories, are often doing it not for financial gain, but so that others do not have the same negative experiences. This is very different to celebrities who often share stories due to a forthcoming album/book/film launch and sensationalist headlines and imagery is good publicity, yet both are treated similarly.

Of his own experiences, he said; “they sensationalise it, it’s all about the bones showing” (Appendix 11 - Richard Lines 845-46). Richard told his story through different outlets, stating that one journalist was interested in pictures of him at a time he was ‘most ill’. His response to this request was; “when I was ill the last thing I wanted to do was sit and take a picture of myself in a hospital bed thinking the Daily Mirror might need this in 2013” (Appendix 11 - Richard Lines 846-48). Importantly, this request for imagery was two years after the release of Beat’s (2011a) media guidelines, asking for such reporting and
imagery not to be used. All Richard gave was a picture of himself as a portrait of recovery. He said of being asked to show images of him being at his worst, “I just didn’t want to show any images like that because that’s not mental health, that’s not anorexia. That’s the wrong image of anorexia to put out there, it’s the wrong image about eating disorders. Eating disorders, yes are about foods to some extent, but it’s a mental health condition first and foremost and it’s not focused on that” (Appendix 11 - Richard Lines 852-56). Richard was rejected by one media outlet when the images he provided; “weren’t revealing enough” (Appendix 11 - Richard Lines 954-55). It can be interpreted that the images were to be revealing in order to ‘sell’ the story, both monetarily and artistically, this though serves to reinforce stereotypes, and given the media’s role within the creation of social capital, it can be seen as a vicious cycle which propagates the status quo.

During his interview Richard said he was never asked about his feelings and thoughts when giving interviews or the triggers behind his ED, it was; “all about ‘so you were this weight and that weight’ and ‘oh my god that’s such a lot of weight you’ve lost’” (Appendix 11 - Richard Lines 858-59). Comments such as these would be difficult for Richard, as they could have indicated a journalist fishing for information, a lack of understanding of anorexia or indeed just a normal shocked reaction.

A further poor experience was a graphic and lurid headline in a media article used to describe Richard’s journey. Sensationalist words were used and it referenced his closeness to death, and, in addition, imagery was used to emphasise Richard’s starting size and his lowest weight. Richard stated that he was; “fuming” (Appendix 11 - Richard Line 861) at this. Reflecting on his experiences, Richard said; “my experience I was telling was personal to me. They [the media] didn’t care about that, they wanted a headline grabbing story to glamorize pictures of my bones sticking out. I wasn’t prepared to do it and I still won’t do it” (Appendix 11 - Richard Lines 868-70).

11.7.3.2 - Fighting for The Media, Seeing the Other Side

Although being critical of the media, based upon his experiences, Richard felt that it was too easy to blame the media; “I do feel sorry for the media in some sense because they are in a catch 22” (Appendix 11 - Richard Lines 879-80). He continued to say ED charities must shoulder their share of the blame. Richard used the release of Beat’s Media Guidelines (Beat, 2011a; Beat 2011b) as an example, stating; “they never once worked
An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

with the media and asked them what they thought about it [the guidelines]” (Appendix 11 - Richard Line 884). Richard continued. saying; “work with the media and produce the guidelines…. don’t just use the charity and say this will be your guidelines, like Beat have done and MENGET have done” (Appendix 11 - Richard Lines 882-83). Whilst Richard’s opinions on this subject may or may not be correct, he does have direct experience of volunteering. It must be stated that Beat’s Media Guidelines state clearly in the introduction that;

The guidelines are not exhaustive, and don’t seek to impose on the freedom of the media, but they do aim to help journalists resolve reporting dilemmas, de-stigmatise eating disorders, and increase the public understanding of these complex and challenging conditions to everyone’s benefit. (Beat (2011a) p. 3)

This in some ways challenges the tone of language used by Richard. However, writing this section in 2016, Beat’s guidelines have not been updated since originally published in 2011, which does provide credence to his thoughts about the accuracy of the statistics used.

Continuing upon this theme, Richard felt that blaming the media was a fault in many charities, calling it a “blame game” (Appendix 11 - Richard Line 892) as the media is easy to blame. He added the following pragmatic advice;

If you’re going to survive as a charity or organization you want to help these people get the awareness out there they have to work with the media, otherwise the media will close all the doors and access and you won’t get any of it and you will be stuck in the same situation. (Appendix 11 - Richard Lines 894-97)

11.8 – A LIFE AFTER ANA

“It’s changed my life, changed it for the better and also for the worst” (Appendix 11 - Richard Line 902). In this quote Richard’s initial answer, when asked about the role of anorexia, expressed its positive effect in his life. The positive effects of his ED were attributed to the section of his life where he felt popular, gained a degree of confidence and experienced things that he felt he would not have when at his highest weight. There was also the work he did volunteering to try and help people with EDs; without his ED he would never have engaged upon this work which gave him purpose.

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However, his new identity was not without consequences. Due to his large amount of weight lost, Richard’s body was covered by loose skin, which he could only get removed privately. Richard stated; “there’s not a minute goes by I don’t feel conscious about how I look” (Appendix 11 - Richard Lines 905). He continued to suggest he felt his mental health would be much better if he could get rid of the skin saying;

I don’t ever feel normal, every time I walk down the street, I can’t describe it, I feel like I’m going to pass out because I feel conscious of people staring at me on the bus, bringing all that anxiety back from years ago. It’s not fat anymore, its skin I’ve replaced it with. (Appendix 11 - Richard Lines 908-911)

Richard felt that in some ways he had exchanged one set of problems for another, where he once stuck out for his size, being over twenty stone, he felt that at interview he stuck out because of his skin. Richard spoke of feeling constantly conscious of people staring at him, yet rationally whilst he could not hide his size, his loose skin is beneath his clothing and not plainly visible. Such thought processes could indicate his mental health is still fragile and that he feels every look he receives is a negative one. It also exemplifies his post anorexia diagnosis of body dysmorphia, which although post ED, links to Bramon-Bosch et al., (2000) and Raevuori et al.’s, (2009) findings on the co-morbidity of other mental illnesses and EDs.

Richard’s final comment was; “I’m back to square one again I live half the life I should live” (Appendix 11 - Richard Line 916), which is extremely disappointing for him and shows the correctness of his statement when discussing his experience of the media; “eating disorders, yes are about foods to some extent but it’s a mental health condition first and foremost” (Appendix 11 - Richard Lines 955-56).

11.9 – KEY POINTS FROM RICHARD’S STORY

• Personal and Background
  o Parents split up (his father came out as gay).
  o Low income which was represented in food choices available to parents.
  o Raped as a child by a family member.
  o Richard is gay, as are his brother and sister.
  o Isolated growing up, partly due to moving between his mother and father and the family moving.

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Gareth Lyons
Identified as obese as a teenager.
Identified as being masculine and rejected traditional masculinity.
Accepted the existence of gay sex roles but rejected the idea of all gay men following them.
Found as he lost weight his libido increased although as his weight decreased to low weight levels his body shut down.
Found ‘confidence’ a new Richard through the ED as his weight loss pleased others and himself.
Used thinspiration websites, initially he did not realise what they were but, in the end, became a bully on them.

- **ED Manifestation**
  - Restricted food.
  - Exercise.
  - Vomiting.
  - Laxatives.

- **Education Experiences**
  - Isolated at school due to nomadic life.
  - Missed lectures due to his ED.
  - ED reached a peak at university, which saw him hospitalised.

- **Reactions and Treatment Experiences**
  - Collapsed and hospitalised with pancreatic and gall bladder problems, diagnosed with anorexia. Was treated for physical problems not anorexia. When discharged was unable to get treatment which Richard felt was because of his gender.
  - Extremely sceptical about ED professionals who have gained knowledge from books.
  - Identified that when he told people of his ED, a number, including his brother, suggested it was self-inflicted.

- **Work Experiences**
  - Felt his employer was not supportive as his illness was mental rather than physical such as cancer.

- **ED Portrayals and ED Charities**
- Felt portrayals create stigma and gender inequality as they do not mention men. Felt this was in part due to a feminist drive against men and masculinity in wider society.
- Was highly critical of Beat, labelled the charity as a “Money Whore”, and felt MENGET was more about the founder than EDs.
- Richard was critical of the media within his own experiences but felt that in order to promote EDs they need to be constructively worked with.
CHAPTER 12 - EMERGENT NARRATIVE THEMES

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons
Table 6 on the following page indicates at a glance some of the experiences and behaviours which are shared across the men’s narratives. From this table it should become evident how the main themes within the discussion which follows were formed.
Table 6 - Common Experiences/History from the Interviews

<table>
<thead>
<tr>
<th>Background</th>
<th>Henry</th>
<th>Michael</th>
<th>Stephen</th>
<th>Kevin</th>
<th>Alan</th>
<th>Russell</th>
<th>Richard</th>
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<tr>
<td>Overweight Pre ED</td>
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<td>Social Isolation</td>
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<tr>
<td>Bullied</td>
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<td>Y</td>
<td>Y</td>
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<tr>
<td>Potential issues in family background – (e.g. mental health illness, overweight, physical ill health, divorce)</td>
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<td>Y</td>
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| Education                                                                 |       |         |         |       |      |         |         |
| Education: Degree or Above                                               | Y     | Y       |         |       |      |         | Y       |

| Stated                                                                |       |         |         |       |      |         |         |
| Identified having an ED before their diagnosis                          | N     | N       | N       | Y     | N    | Y       | N       |
| Ignored by GP at first instance                                         | N     | N       | N       | N     | N    | N       | N/A     |
| Experienced gender issues/stereotyping/barriers when accessing and/or during treatment | Y     | N       | Y       | Y     | N    | N       | Y       |
| Masculinity                                                             |       |         |         |       |      |         |         |
| Rejected ‘traditional masculinity’                                       | Y     | Y       | Y       | Y     | Y    | Y       | Y       |
| Employment                                                              |       |         |         |       |      |         |         |
| Identified ED effected capability in education and/or at work            | Y     | Y       | Y       | Y     | Y    | Y       | Y       |
| Accessed ED charities before treatment                                  | N     | N       | N       | Y     | N    | N       | N       |
| Charities and Portrayals                                                |       |         |         |       |      |         |         |
| Had negative experience of ED charity(ies)                              | Y     | Y       | N       | Y     | Y    | Y       | Y       |
| Concerned about lack of male portrayals of EDs                          | Y     | Y       | Y       | Y     | Y    | Y       | Y       |

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons
Four clear themes emerged from analysing the data across all seven narratives. The themes are:

- **The Final John Doe**
  - The men’s background stories showed many similarities with existing literature, it was imperative that a theme comparing and contrasting the men’s stories was included.

- **Masculinity – The Beast in Me**
  - Examination of the men’s stories around their constructions and beliefs surrounding masculinity, including a scenario where gay men were more ‘traditionally masculine’ than heterosexual men.

- **Not Working 9 to 5**
  - An account of the men’s experiences around employment and their ED.

- **Help! I Need Somebody – Bedlam Revisited**
  - Issues around the men’s treatment experiences, their experiences and opinions of seeking help, media and the voluntary sector.

### 12.1 – THE FINAL JOHN DOE

Within the literature review a sub-section (2.6.2) was titled ‘Mr Potato Head’ – The John Doe Male Anorexic, drawing together the literature to form a ‘photofit’ of a male experiencing anorexia. After having looked at the data gathered from the demographic questionnaires and the analysis of each of the interviews within this study, John Doe can be re-examined and compared with the men who took part in this study.

#### 12.1.1 - AGE OF ONSET

The age of onset for men experiencing anorexia, or the time the men believed they first displayed ED characteristics in this study was within the range 14-27 years (14, 15, 15, 15, 16, 21, 27); the mode being 15, the average age being 17.5 and the median 15. This was broadly aligned with published literature, different ages of onset between 15 and 21 were identified (Fassino et al. 2001; Crisp et al., 2006; Lindblad et al., 2006; Gueguen et al.,...
2012). However, only Alan (15 years) and Stephen (14 years) were diagnosed and in the health system at this point.

12.1.2 - FIGHTING THE SCALES PRE-ANOREXIA

A number of studies (Cooperman, 2000; Strober et al., 2001; Fernández-Aranda et al., 2004; Raevuori et al., 2008; Raevuori et al., 2009; Gueguen et al., 2012) found men with EDs had at some point before their illness been overweight, unlike women with EDs. These conclusions appear to have been corroborated by the men within this study. Five of the seven men with anorexia reported being overweight, and three talked of being bullied in one form or another because of it. Only Stephen and Henry reported not being overweight, however both reported delayed puberty indicating being underweight rather than overweight. Both Henry and Stephen reported that others in their immediate family had experienced problems with their weight.

12.1.3 - THE WHY AND HOW? - THE GOAL OF EATING DISORDERS

Both Cooperman (2000), Dissing et al. (2011), Grossbard et al. (2012) and Núñez-Navarro et al. (2012), indicated that men with anorexia tended to see their behaviour as some kind of effort to become more toned. These findings are in keeping with the stated aims of the heterosexual men in this study who reported their efforts were to lose weight to tone and become fitter. This was different from the gay men who desired to lose weight to become thinner.

12.1.4 - METHODS (APART FROM STARVATION) OF LOSING WEIGHT

Literature indicates that the main form men used to lose weight outside of food restriction is to engage in exercise, often excessively (Bramon-Bosch et al., 2000; Mangweth et al., 2003; Raevuori et al., 2008; Dissing et al., 2011; Murray et al., 2012; Younis and Ali, 2012). Six of the seven men reported exercising as a means to lose weight. Kevin for example, during his interview reported running between 30-40kms a week. Alan said that he ran for 60kms a week and Russell spoke of using a rowing machine for at least one hour a day. Such evidence reinforces the popularity of extreme exercise as a way of men controlling their weight, perhaps this could be because dieting within men may be seen as
feminine. Linked to this are the choices men make, in affect regulation. Due to the impact of stigma, exercise has been found to have more positive psychological benefits for men than women, as it also allows men to engage in rigid practices (Murray et al., 2014).

The similarity with literature was not as clear cut when it came to other forms of weight control. Both Button et al. (2008) and Núñez-Navarro et al. (2012) found vomiting to be a more preferred method used by men to control weight compared to laxatives. However, the men in this study reported using vomiting and laxatives equally. What was interesting was the two gay men who participated in this study stated they had used exercise, vomiting and laxatives, as well as restriction. This perhaps would indicate a greater or quicker need/desire to lose weight; this may be due to the sexual benefits of being thin that the gay men reported during interview. Furthermore, the most extreme method of weight loss was by Alan who was the only man to fully engage in gay culture. Alan reported using diet pills and amphetamines, as well as the other methods, to lose weight. These conclusions reflect those of Russell and Keel (2002), who noted that gay men exhibited greater body image dissatisfaction and ED symptoms than heterosexual men.

12.1.5 - FAMILY BACKGROUNDS

12.1.5.1 - Weight Issues and Dieting

The family backgrounds of people with EDs have for obvious reasons, such as exposure to behaviours, trauma and attachment, been taken account of in terms of why people may have mental illnesses. Crisp et al. (2006) found that the men in their study shared family backgrounds, which consisted of one or both parents being either overweight, suffering from their own mental health problems or both. An examination of the narratives of the men within this study would appear to confirm Crisp et al.’s (2006) conclusions. All of the men reported parents either having weight problems or mental health problems. Stephen reported both. However, a cautionary note to this, and similarly with Crisp et al.’s (2006) findings, is that both Michael and Alan reported their mother’s being constantly on diets, but did not use the term overweight. Kevin, who said both his parents were overweight, and felt his father has suffered from depression although had never been diagnosed.
12.1.5.2 - Overprotective, Indifferent and Abusive Families

For a number of years, it has been suggested males with anorexia tended to have overprotective mothers (Crisp and Toms, 1972; Tong et al., 2005). The narratives of Henry, Russell and Alan all indicated strong and close relationships with their mothers. Henry and Russell spoke of episodes that could be construed as being overprotective; in Henry’s case, it was his mum’s reaction to his ED and for Russell it was the role of his mum in his disagreements with the NHS mental health team. Alan’s case could be viewed differently, in that being brought up by a single parent until the age of eleven, and having no contact with his father, it is perhaps no surprise that he has a close relationship with his mother. Michael and Stephen did not make any comments as to if they were closer to one parent than another. Kevin indicated feeling closest to his maternal grandfather and then his dad, although when speaking of his family’s reactions to his ED it appeared his relationship was distant, and he did not tell them about seeking treatment until a year after the event. Richard’s relationship with his family appeared quite fractured, as during childhood he lived with one parent and then the other, moving many times. He also stated that he had received no help from his parents in relation to his ED. Richard spoke of being raped as a child by a close family member, with the literature suggesting EDs were often a way people deal with sexual trauma (Harned and Fitzgerald, 2002; Buchanan et al., 2013). However, the findings of this study did not replicate those of Mitchell et al.’s (2012), where nearly 70% of the men diagnosed with anorexia in their study reported being sexually assaulted.

12.1.6 - ISOLATION, SEX AND SEXUAL IDENTITY

12.1.6.1 - No Man Is an Island

The men in this study reported that they felt isolated before and during their ED experiences, for some it would appear their isolation continues. The men struggled for different reasons to make friends. For example, Michael felt he became isolated after an episode in primary school where he got some members of his class into trouble. Richard struggled to make friends because he moved around a lot as child and felt that he had to be more mature than his peers. Alan was bullied for his weight, Stephen for his teeth and haircut. Kevin felt he was introverted, Henry said that growing up he did not feel isolated.
but described himself as being a “sociable loner” (Henry Line 189). What Henry means by this is open to interpretation, but my interpretation is of someone who can get on with different people, but does not fit into any groupings and, as such, is always an outsider. Only Russell did not report isolation growing up. This is conceivable, as his first experience with an ED was in his late twenties and up to that point, from his narrative, he had lived a ‘normal’ life. In the main, the men’s narratives supported the link between EDs and isolation evident within literature (Lindblad et al., 2006; Raevuori et al., 2008). During their EDs both of the gay men in the study reported being more sexually active, with Alan stating that he felt his isolation reduced because he was attracting sexual partners. However, Alan, post ED, struggled to see intimacy as a romantic act, perhaps indicating that he may have become physically less isolated during his ED, but psychologically it had the reverse effect, perhaps compromising his ability to be intimate.

12.1.6.2 - Sex and Relationships

As discussed within the literature review and in the previous paragraphs, anorexia is a mental health problem which promotes isolation, albeit social isolation from friends and/or family. In addition, there is also the more personal romantic isolation from relationships. The importance of physical relationships was highlighted by a number of researchers; Crisp et al. (2006) (being sexually active before ED provides a better prognosis for recovery) and Brown and Keel (2012) (relationships can be a protective factor, although the sample in their study was men with bulimia). Mehler et al. (2008) reported that 78% of their sample was not involved in a relationship, with Gueguen et al. (2012) demonstrating a similar finding. Of the seven men interviewed in this study, it seems that only Russell, the eldest man at age of onset, was in a relationship when his ED behaviours started. Henry, Michael, Stephen and Kevin stated that they were not in a relationship, with Henry and Michael sharing that they had never been in a sexual relationship before their ED. Stephen, it could be suggested, indicated this when stating; “I haven’t ever been in a proper relationship as I have no self-confidence and self-worth” (Stephen Lines 47-48). From Alan’s narrative, it was difficult to establish if he was sexually active or in a relationship at the time of onset of his ED. However, it could be argued with the turmoil in his life at that time and his isolation he probably was not in a relationship, but he did not conclusively say either way. Given the men’s stories, engaging in relationships appears
problematic for men with EDs (Mehler et al., 2008; Gueguen et al., 2012). This left two men who stated that they had sexual relationships before their ED, leaving one man where it could not be deduced one way or another. Evidence suggested men who have not engaged in relationships before the onset of an ED are likely to have a poor prognosis (Crisp, et al., 2006).

As well as psychological isolation pre and during the ED, the physical effects of food restriction and the stress of the ED also had an impact upon physical relationships. Both Henry and Stephen reported delayed puberty which was still impacting upon them in their mid-twenties. All of the men, with the exception of Richard and Alan, reported a loss/lowered libido or asexuality, with similar findings being reported in existing literature (Hall et al., 1985; Freeman, 2005; Lindblad et al., 2006; Agalusca et al., 2012). For Russell, in a relationship, this decrease in his sex drive and desire was problematic. Russell said about his lack of libido that he was;

Annoyed I think because I am conscious of it and because you can obviously tell she’s itching you, kind of force yourself into it but at the same time I’m not that bothered about it if that makes sense. It’s definitely more instigated by her than me these days. (Russell Lines 984-87)

The two gay men who took part in the interviews appeared to have bucked the trend of reduced libido and sexual drive, as they both stated that, unlike the heterosexual and bisexual men in the study, their sexual activity increased. Closer inspection of the data suggested that as these two men lost weight, and it is assumed became more attractive, they went through a period of sexual activity. Alan felt that this attractiveness to other men fuelled his desire to become thinner, but he did note that his libido fluctuated, and when prescribed anti-depressants it was non-existent. But he described his life as starving himself during the week, having a high of sex and/or drugs at the weekend and then feeling remorse and starving himself again.

Richard had a similar experience to Alan; as he lost weight, became more ‘attractive’ and found that he was able to attract partners, stating that his sex drive increased. However, later in his narrative, Richard spoke of having prolonged bouts of sleep where he lost days of time, was physically unable to move, and eventually became so unwell he was hospitalised. It is therefore prudent to speculate that his increase in sex drive may well have reduced as his body shut down. This would be in keeping with studies on starvation...
such as (Keys et al., 1950). However, the stories of both Richard and Alan, show that sexual drive, whilst being linked to physical health, is also linked to psychological well-being, and is perhaps not as good an indicator of the seriousness of an ED as previously thought. Richard reported an increase in sex drive, yet was the only man in the study who reached a point where he collapsed and his first experience of medical services was being taken by others to the hospital with organ failures.

12.1.6.3 - Sexual Identity

Statistically the typical man with anorexia is heterosexual, although this factor is often lost due to the elevated levels of gay men who present with EDs compared to society in general. Gay men made up 20% of participants in Fassino et al.’s (2001) study, whereas in the general population (within Italy) the figure was 4%. In the U.K. 2.1% of the male population identified as being gay/bisexual, with 4.1% refusing to answer the question and 0.4% stated other, this left 93.5% who identified as heterosexual (The Office for National Statistics, 2016). In this study, the men were asked for their sexual orientation of which two identified as being gay, one as bisexual and four as being heterosexual. Therefore, there was a 40/60 split between gay/bisexual and heterosexual men, double that in the sample in Fassino et al.’s (2001) study. This statistical imbalance can be explained in a number of ways. One explanation could relate to the participants being men who engaged in ED activism, because of the stigma of EDs being associated with a female illness (Raevuori et al., 2008; Jones and Morgan, 2010; Murray, 2014). For gay men who are more feminised this stigma will not be as great as that for a heterosexual man. It is therefore perhaps easier for them to take a more active role, especially as the hierarchy of MENGET is openly gay. However, with such statistical imbalances, re the number of men who are gay with EDs as opposed to the number in society, it is no surprise that homosexuality was identified as a risk factor of EDs (Weltzin et al., 2005).

12.1.7 - CONCLUDING WITH JOHN DOE

The men who participated in this study broadly fell into the generalised characteristics of a male experiencing anorexia. There were many more areas of overlap than divergence, such as age of onset, troubled family backgrounds, pre-anorexia weight problems, social and
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Meyer et al. (2001) reported that femininity is a risk factor in eating disorders, whereas masculinity is likely to be a protective factor. It was therefore important to ask the interviewees for their own views and constructions of masculinity. What was clear was that masculinity can mean many things to different people. In its simplest form it is almost the rules a man lives by. It was clear from the narratives that the men held both similar and contrasting views about masculinity. It was interesting to hear that some of the men verbally rejected stereotypical masculinity yet then used it as a yardstick for their own self-worth. Masculinity is an important theme and an area of future research; the men interviewed as a group have low self-esteem and confidence and this comes from how they see and they compare themselves to others.

Whilst the purpose of the narratives was to gain insights into the lives of those interviewed, themes emerged which focused around masculinity, from rejection to the reinforcement of hegemonic masculinity (Connell and Messerschmidt, 2005). However, whilst there is an existent literature on male masculinities (Connell, 1995; Hutchins and Mikosza, 1998; Courtenay, 2000; Bourdieu, 2001), the men interviewed seemed to subscribe to the thoughts of Flood (2003) who argued, “The best kept secret of literature on men and masculinities is that we have very little idea of what we are talking about when we use the term masculinity” (p. 203). The narratives from the men interviewed for this study support Flood’s conclusion, as collectively they both championed and challenged social constructions of male masculinity.

Masculinity comes from one’s experiences, interactions and thoughts and as such is constructed via social capital through our societal structure; family, friends, clubs, schools, workplaces. Each man’s masculinity or development is unique to him and is fluid, in terms of it being temporal, his exposure to differing experiences and the role he believes he needs to fulfil at a specific time. Ideas of who we are and what we should be change over our lifetimes (Spector-Mersel, 2006). While our developmental ideas change over time (Bruner, 1961), masculinity theory seems to be fixed on men in their prime (Connell and
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roles, but his friendships and work groupings saw him having different levels of masculinity within them.

12.2.1.2 - When Gay Men Are Closer to Hegemony Than Straight Men

One of the most interesting sub themes to come from the narratives was how the gay men may be considered to be more hegemonic than a number of the straight men in the study. Hutchins and Mikosza (1998) described how when Ian Roberts, an Australian Rugby League player, came out in the early 1990s he was not vilified due to him fulfilling hegemony much more than his straight opponents through his aggression, competitiveness, achievements and physical attributes. This shows some fluidity in masculine thinking and provides context from what emerged from two of the men in the study. The two openly gay men in this study both spoke of how their EDs boosted their sex lives because their lower weight had made them more attractive to potential partners. Both men talked about sex via promiscuity rather than within established relationships, and it is ironic that sex, and in this case non-relational sexuality (Levant, 1992), one of the bastions of hegemonic masculinity for the straight men, was non-existent during their EDs. All of the straight men and the bisexual man reported loss of interest in sex. For the men who before their ED had not been in a relationship, isolation became more acute. Russell was in a relationship whilst having an ED and he reported sexual problems, from embarrassment in appearance to a lack of desire.

Whilst strictly speaking, within hegemonic masculinity, it is meant that sex should only be heterosexual, and some would suggest that it is an act of domination (Flood, 2003); whereas gay sex in any form is not hegemonic, even more so in the submissive partner who is often seen to be more passive or dominated (Kippax and Smith, 2001; Tskhay et al., 2014; Valentova et al., 2014). This ‘masculine role reversal’ does illustrate that whilst all of the men were losing weight, it was only the gay men who saw an increase in sexual activity. Why this was the case is open to interpretation. Perhaps within gay sex roles, younger men, as suggested by Alan, are “supposed to be passive and quiet and demur and sexualised” (Alan Lines 620-21), in parallel with the role of women within the frame of Hegemonic Masculinity. Taking this idea and transposing it to heterosexual men, due to sex role stereotypes, perhaps even when their appearances had improved (Michael talked about positive comments about his appearance), they may still have lacked the confidence.
to approach women, as would be expected within a hegemonic framework rather than them being approached. In contrast, both gay men became more androgynous/feminised, fitting into to gay sex roles (even if Richard did not actively pursue this culture). Regardless of how the men’s narratives are interpreted, it still makes extremely interesting debate for future research.

12.2.2 - SPORT AS A GUIDE OF MASCULINITY

The men were all asked about their views of masculinity and as a group they all felt emasculated, with only Richard and Russell speaking positively about their masculinity. Some, such as Stephen and Richard, questioned traditional masculinity, whereas a number of the men questioned their own masculinity. Interestingly sport and football were often used as some kind of yardstick. Views ranged from; “I have never been a particularly masculine man, I didn’t really play contact sport at school, and I am not particularly sporty. I like musical theatre” (Kevin Lines 148-49) to “I don’t like football either, but it doesn’t mean I’m any less of a man because I don’t like it” (Appendix 11 - Richard Lines 697-98).

The use of sport is extremely interesting. Swain (2000) identified how football in the playground at school was used as a way of creating masculine domination and hierarchy. When football was not allowed, schoolboys found other ways to gain popularity and prestige through other physical and athletically competitive games (Swain, 2002). Connell (1995) wrote “masculinity exalted through competitive sport is hegemonic; this means that sporting prowess is a test of masculinity even for boys who detest the locker room. Those who reject the hegemonic pattern have to fight or negotiate their way out” (p. 73). This introduction to competitive sport begins early in life for boys and, for those who do not enjoy it, will find that from an early age they are ‘different’. This promotion of a masculine hierarchy could also be used to contest hegemony such as gay men not engaging in team sports (Robertson, 2003). The use of competitive sport, primarily team sports, as reinforcement of hegemony is interesting, as when the men in this study decided to lose weight they chose individual sports such as running, cycling and rowing. It could be suggested that they were unconsciously rejecting hegemony, although one
could counter that these forms of exercise allowed them to train without others watching over them to hide embarrassment over performance or appearance. However, the isolation this caused still saw them withdrawing from social groupings.

12.2.3 - MASCULINITY THROUGH EXCESSIVE EXERCISE AND FOOD RESTRICTION

The men ironically showed signs of what in different circumstances could be viewed as hegemonic masculinity. Russell, for example was the only man to mention how he used his competitiveness to make himself restrict and exercise harder. It is possible, if not probable, that the other men engaged in competition, even if only with themselves. Russell typified this when talking about his engagement with the My Fitness Pal App

The app was very good to begin with but it sort of reached this point that it all became a bit of a challenge, that you've done this much exercise today you've got this many calories to burn off or to eat so it would be useful. (Russell Lines 30-32)

The men in the study may reject masculinity or believe they do not conform to it, but they all displayed a competitive edge, a key trait of masculinity identified in the literature (Donaldson, 1993; Swain, 2000; Connell and Messerschmidt, 2005). Whilst primarily seen as competitiveness over others, the competitiveness the men showed to lose weight can perversely be seen as an achievement over themselves. This is paradoxical; that when showing such hegemonic masculine traits as stoicism, mental toughness, risk-taking, competitiveness and success (Donaldson, 1993) in their drive and actions to lose weight, the men effectively emasculated themselves.

A further example of the unease with the relationship with masculinity, is exemplified within the heterosexual men in this study, who all reported the desire to lose weight to become more toned/athletic. According to Grossbard et al. (2012) this is in accordance with masculine gender norms. The interpretation of these men’s narratives centred on their beliefs that being thinner or more toned would be a panacea to their problems, especially those relating to their isolation. It must be stated that even though these interpretations are based upon the unconscious, all of the men in the study made a conscious decision to try and change their appearance/improve fitness, like so many people without EDs, and at some point in this process the ED took over.
12.2.4 - MASCULINITY AFFECTING TREATMENT?

Early diagnosis of illness is a key factor in successful treatment. Räisänen and Hunt, (2014) found that men with an ED only recognised their illness after a protracted delay. Excluding Alan and Stephen, who were taken to their GPs by adults both being under 16, the rest of the men who participated in this study did not directly say that their masculinity prevented them from going to seek help earlier in their illness. Literature indicates this could be a factor attributable to them, they all realised something was wrong, but waited to act upon it. Richard collapsed and was taken to hospital, Henry went when he felt on the point of a nervous breakdown and Michael only saw his GP as he felt he had meningitis, he said,

I was getting worse so I knew something wasn’t quite right. I could see the weight going down and I had it; there were all these posters up around university (and I don’t think anyone believes me when I say this) and it was all about meningitis and there were all these symptoms; ‘are you feeling really tired? Is your skin looking terribly?’ And I was getting quite worried that I had meningitis or something. (Michael Lines 258-67)

O’Brien et al. (2005) wrote that men’s views of their own masculinity showed; “too many participants to (be seen to) endure pain and to be strong and silent about ‘trivial’ symptoms, and especially about mental health or emotional problems, was a key practice of masculinity” (p. 514). This resonates with the men in this study.

At the beginning of this section a quotation by Flood (2003) was used questioning our understanding of what the term masculinity means. The majority of men who participated in this study did not feel that they were masculine, because they did not conform to cultural stereotypes. Kevin, as well as linking his masculinity to sport, also questioned it because he liked musical theatre. Some men, such as Stephen and Richard, questioned these stereotypes rejecting the idea of traditional masculinity saying; “it means nothing nowadays” (Appendix 11 - Richard Line 667).

While all the men may reject or not believe in masculinity, what was clear from their narratives was that they had showed a number of masculine traits in their dietary restrictions, excessive exercising and their reluctance to seek help. However, a number of other masculine traits were shared in their narratives which the men may have never considered as positive. For example; five men held graduate degrees or higher
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qualification which showed mental toughness and measurable success. A number of the men held/or had held jobs with levels of responsibility over others (power) as well as being financially well rewarded (success).

What this shows is that masculinity is not a black and white set of rules which can easily be generalised. Each of the men had differing thoughts and whilst there may have been areas of agreement there were also differences.

12.3 – NOT WORKING 9 TO 5

Asking the men about their experiences of employment and their eating disorder was an area that was important to me because of my own personal experience. It was a topic which did not surface within the literature review, which is not surprising given the clinical focus of the literature. The reason for asking such questions was as stated, because of my experiences, and to ascertain what aspects of the men’s lives were or were not affected by their ED.

Simplistically a full-time employee will work approximately 40 of the 168 hours in a week (including weekends), if they get the recommended eight hours of sleep a night (56 hours a week). This equates to spending approximately 36% of their waking hours in work; this does not include commuting or getting ready for work. A large portion of our life is lived in work, going to work, coming home from work and thinking about work. Work enables the structuring of time, an important psychological concept for human beings as it provides purpose to life (Berne, 2016b). It has been suggested that in order to succeed in business an employer needs to look towards their employee’s mental as well as physical wellbeing, as an unmotivated or unhappy worker is not a productive one (Herzberg, 1987). From a psychological standpoint, researchers, such as (Zhao et al., 2007), have written about the ‘Psychological Contract’ in the workplace, an unwritten addendum to the contract of employment which loosely can be described as the expectations of the employer and employee. Zhao et al., (2007), concluded that breeches in this contract by either party could have significant impact upon behaviours and attitudes within the workplace. It is the employee’s responsibility to fulfil the performance and provide the results expected, and for the employer to look after their employees’ well-being and safety, a phenomenon in
keeping with Berne’s (2016b) theory of the non-personal strokes people engage during pastimes.

While stereotypically, an ED is portrayed as a teenage illness, with ramifications on wider life issues being referred to as the postponement of exams for a year, for adults, with much more fiscal responsibility the effects of the illness may be more complex. Simplistically, adults with illness often have the dilemma of not being physically/mentally able to work, but feeling they have to do so. In the literature, this is termed ‘presenteeism’, often associated with a number of factors including the person’s financial responsibilities (Miraglia and Johns, 2016). The opposite of presenteeism is to step away from work. Kevin, for example, found that he had to take long term unpaid leave (approx. 12 months) from his employment in order to engage in treatment. Whilst not ascertained if he asked for paid leave, the effects of the ED are quite apparent when he lost 12 months wages and pension contributions having to live off his savings. Russell, terminated his main employment in order to try and improve his health. Both men stated they were lucky to be able financially to step away from work, although Kevin was worried about the implications about having to potentially take more unpaid time off work. Treasure (2005) wrote about the effects of anorexia both physically and mentally, a number of these potentially applying to the work place. These include, but are not restricted to, reduced concentration, lower problem-solving skills, impairment of complex thought, reduced physical strength.

The ED charity Beat released basic guidelines in conjunction with the Employers Network for Equality and Inclusion for Employers (2016). It stated that approx. 2% of the working population are affected with an ED and they are protected legally by the Equality Act (2010). The guidelines indicate how employment worries can cause issues for people with EDs. Beat (2015) published the cost to the U.K. economy of EDs as £15 billion per year, with approximately half of that being attributed to health care costs and £6.8 to 8 billion being classified as “lost income to the economy” (p. 9), the latter relating to sick days and lost productivity. In real terms, this equated to between 0.36 and 0.43% of U.K. GDP (£1,865,410m 2016 – figure)(Office for National Statistics, 2016). One troubling aspect of the report is
Employees with eating disorders often present little difficulty at work and excel at their job. Whatever difficulties they have, they are likely to make strenuous efforts to keep their illness to themselves to avoid their disorder being noticed at work. The work situation does not, in itself, cause someone to develop an eating disorder. (p. 8)

This downplays the potential effects of EDs, the severity of the symptoms highlighted and the fact that it has the highest mortality rate of any mental illness (Klump et al., 2009).

When analysing the men’s narratives, it appeared that asking about their employment was justified as their shared experiences encompassed a range of problems relating to employment; from the employer understanding, to physical and mental capability. Further research into this area would be fully justified. All of the men experienced problems at work because of their ED. In some cases, this was because of not wanting to share their diagnosis, in other cases this was because of their concerns about the employer’s reaction. For some of the men interviewed this led to a change of career, others put their career on hold and one man could only work part time.

12.3.1 - TO SHARE OR NOT TO SHARE?

From analysing the narratives, it would appear the men were reticent to share their history on application forms or at interviews; five of the seven men indicated an unease at potential reactions and stigma. This was consistent with the work of Toth and Dewa (2014). Kevin was the only man who shared his ED straight away with his employer and this was perhaps because of the nature of his employment and his need for security clearance, rather than a desire to share. This disclosure led to him having to see occupational health and having his health history being graphically shared with his superiors. Within his narrative Kevin seemed to be uneasy with this situation, and more specifically, with the language used in reports about him.

Henry and Alan adopted similar strategies in which they offered vague answers to any potential questions regarding the chronological gaps in their employment history, merely stating it was due to ‘illness’. It could be construed that this would lead to employers becoming even more wary of their applications. Alan said “I usually put other, at the bottom mental health [application form illness questions], and then specifically mentioned it to my manager after I had been there a week and judged by their character that this was
an issue” (Alan Lines 530-32). He felt his employer would be more receptive at this point. In his narrative Alan stated that when he had disclosed, he had had no issues with his employers due to his ED. Henry, on the other hand, disclosed his ED to his most recent employer, and although he was offered the job, he felt obliged to give verbal guarantees as to his competency to work.

Research indicates that people with mental illnesses in general are loath to disclose their illness to employers, unless it is clear to them that the benefits of doing so outweigh the negative consequences (both real and perceived) (Mind, 2011; Toth and Dewa, 2014). In a national survey Mind (2011) reported 70% of respondents believed that their superior would not be helpful if they disclosed a stress related illness, with 20% of respondents believing disclosing such an illness would lead to them becoming the first in line for potential redundancy. The NHS reported that 47% of people with a mental health problem had experienced discrimination within work, whilst 37% had experienced discrimination searching for employment (NHS Employers, 2008). These statistics are legitimised through research such as Stuart (2006), who found direct and indirect discrimination, from negative attitudes towards people with mental illness from employers and workmates.

The decision as whether or not to share information regarding one’s mental illness is extremely problematic; if a person with a mental health problem does not come forward with their condition then their employer cannot do anything to help or make adjustments to their working conditions. If they do come forward they face possible negativity, and if they do not own up to such problems they face potential difficulties with their condition affecting their work. As stated above, the perceived benefits must outweigh the negatives for someone to feel able to come forward and open up in regard to their mental health problems.

However, the decision whether or not to share information re mental health problems is not helped in the sphere of EDs by a lack of understanding of their effects and implications. The Equality Act 2010 lists ‘eating disorders’ as a condition covered by the Act, (H.M. Government Office For Disability Issues, 2010). It is therefore somewhat disconcerting to then read a document by the National Union of Teachers (n.d.) (but post 2010), which lists advice for members to help get reasonable work adjustments from their employers, as the only conditions listed relating to mental health are; Bipolar Affective Disorder, Bipolar...
Disorder, Stress and Anxiety. A similar document by the Trade Union Congress (2013) at least mentions mental illnesses. With these examples in mind it is perhaps understandable that people with EDs may struggle to come forward to their employers when employee representative bodies do not clearly recognise them in their literature despite being listed within the Equality Act 2010. Stephen was in many ways similar to Alan and Henry in not wishing to disclose his ED, stating this was due to him wanting to be treated the same as his colleagues and not being pitied. Stephen, it was assumed, shared his ED with his employer due to the issues he has with his voice where he felt he had to explain its pitch.

The narratives of the men certainly indicated that there is an unwillingness to share information about their illness within the workplace. Stigma around mental illness or EDs, whether perceived or real, seems to be a common theme amongst the men. Stigma has been identified as a stumbling block to men seeking treatment, and, if this is the case for seeking medical help, it is surely not a leap too far to suggest that this may be the case in other areas of life (Paterson, 2004; Soban, 2006; Brown, 2007). Courtney (2000) argued that stigma, and health stigma in particular, compromises masculinity. In our society with stereotypical gender roles, the men in this study not only had to deal with telling their employers about their mental illness, but also had to admit to an illness usually associated with women (McVittie et al., 2005; Raevuori et al., 2008). It is not inconceivable that within traditional masculinity and gender roles within employment, an association with a female illness would be even more traumatic for a man due to his emasculation. Although not relating directly to employment both Kevin and Henry spoke of the stigma of shame because they had an ED, Henry wrote

My own experience with anorexia - one of the reasons I’m reluctant to speak about it in public, personally face it, etc. - comes down to shame. It’s a critical word for me with regard to my illness. (Henry email 15th Jan 2015 Lines 10-12)

12.3.2 - ARE EDS REALLY AN ILLNESS?

Only two men encountered negative responses when sharing their ED with their employer, which in some ways may illustrate the fear of telling about an ED is not totally justified, at least not after a job offer. Richard reported that one of his employers was not supportive, because they did not believe his ED was real, merely something ‘self-inflicted’ and ‘in his head’. Richard felt that he would have received much better treatment if he had been
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Kevin’s experience of his employer’s reaction to his ED was troubling to say the least, partially because of how his job was changed and also because of his employer being the U.K. government. After seeing occupational health, Kevin found that despite his ED, his work load and responsibilities, including those over other employees, were increased. Given his narrative this could be considered incredulous, indicating either a lack of understanding by occupational health and his superiors, or an attempt to get him to leave his job. Kevin believed that this reaction was a factor in him having to take short-term sick leave, because he feared he would make an attempt on his life. Following this he then had to take a long period of unpaid leave in order to engage in treatment. When trying to return to work, Kevin felt that his employer’s reaction was negative rather than constructive. Kevin described how he felt his employer’s language was much more deconstructive and almost unwilling to have him back.

Kevin and Richard’s experiences were not indicative of all of the men interviewed. However, what Kevin and Richard shared indicates that a lack of understanding from employers is potentially a real problem for men (and women) with EDs. This is evidenced in the literature; Klump et al. (2009) suggested EDs were not viewed by authorities as being as serious as other mental illnesses in some countries and parts of America, despite the proven effects, causing problems for people getting treatment.

12.3.3 - TALKING THE TALK, WALKING THE WALK

An unsurprising sub-theme emerging from the men’s narratives on their employment centred on their capability to work being affected by their ED. All of the men either directly or indirectly shared that the ED had affected their ability to work, both physically, and in some cases mentally. Henry spoke of only ever being able to work part time or for short periods in full time work, such as holiday camps. Henry stated that his limited capacity to work was the result of him making himself ill through overwork, not eating and weight loss. On a similar vein, Stephen stated that his energy levels affected his employment and as a result his confidence was much lower. Alan spoke of having to have time off work due to stress and medication changes, this resulted in him undergoing capability proceedings, which he was happy with as it indicated he was being treated the...
same as his peers. Although not directly related to employment, Alan had many problems during university in completing his studies, having to re-sit his second year and finally having to quit in his third year due to being unwell.

Kevin’s narrative suggested that he had thoughts of self-harm involving public transport on his commute, which led to his initial absence from work. This could be interpreted as a question mark over his capacity and capability to do his job. Simply put, if a person is having thoughts about ending their life, their fitness to carry out day to day roles in life such as employment could be called into question, especially if that employment is stressful or involves being responsible for others. People with EDs have been shown to have “significantly impaired cognitive function, judgement, and emotional stability; and restrict the life activities” (Klump et al., 2009, p.97). Kevin’s thoughts are open to interpretation and one such theory could be that the additional responsibilities which were ascribed to him at work after his disclosure, led to him being unable to do his job properly and an internalisation of this fear of failure intensified during his commute towards work each day, resulting in his thoughts of self-harm.

Russell found himself in a similar situation, giving up his role when he felt physically not strong enough to continue with his work. However, he was in a position where he was in control of people’s safety and although he said stepped away from his job before it became an issue, he did report cognitive problems after stopping. It would be interesting to know if Russell recognised these problems at their outset or after a period of time. Although Russell felt he did not enjoy his main job as much as previously, his desire to stop work and eventually change career came with his ED. Treasure (2005) suggested people diagnosed with anorexia have a drive to people please, and interestingly Richard stated that whilst trying to get better he used the people who relied upon him in his employment as a motivator. If Richard used these people to try and get better is it conceivable that in a different person, or even in Richard before seeking help, such motivators could be used in order to continue working. The question of mental health capacity and positions of responsibility, specifically in relation to eating disorders, has been discussed ever since the Clothier Report of 1994. In the narratives of Kevin and Russell they held/hold positions of great responsibility, with people in their care or sensitive government information, and this is an area which needs further examination.

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Gareth Lyons
Michael spoke of how his current job was something that he loved doing, even though it did not pay as well as his other jobs or offer a career path. But in reality, it did provide him with a safe working environment where he could protect himself from the stress he spoke about in his previous career.

12.4 – HELP! I NEED SOMEBODY - BEDLAM REVISITED

One of the themes which came from the interviews which may perhaps be of most interest to the current field of research was the wide-ranging stories about seeking help and treatment the men had experienced. One sub theme which appeared was that the men had different treatment experiences depending on geographical location. This is nothing new and is not surprising, given the assignment of the label ‘postcode lottery’ which illustrated how, pre-2012, funding decisions were made at local primary care trust level, with NHS trusts investing in different areas (Russell et al., 2013) and subsequently introducing disparities in care and/or expertise. Some of the men in the study had treatment before 2012 and others after, but all have faced the possible effects, as pre-2012 issues would not be eradicated overnight. Whilst differences in treatment because of geography may not be a surprise, some of the experiences of the men who shared their narratives were. From the narratives, what was apparent was that a ‘one cap fits all’ approach to an individual’s treatment is problematic, paralleling conclusions drawn by Button and Warren, (2001) and Colton and Pistrang, (2004).

12.4.1 - I HAVE A PROBLEM WHAT CAN I DO?

At some point in their journey all of the men sought help. Some of the men, Henry, Stephen, Michael and Richard did not think that they had an ED and, as in findings of previous studies, it was generally a complete shock for them when diagnosed (Cooperman, 2000; Paterson, 2007). However, it must be noted that this was only half of the men who participated in the study. Of the other four men, Kevin and Russell were the only ones who directly said that they knew they had an ED before diagnosis. However, Kevin stated that he only looked for information re charities after diagnosis and he also lived with his ED on and off for well over a decade before seeking treatment, both of which could indicate a
form of denial on his part. Russell was similar to Kevin in that he was in his late twenties when first seeking help, although his ED only manifested itself shortly before. This left Alan. He told one of his mother’s friends about his behaviours, but it was not clear if he recognised them or not as being associated with EDs.

What was clear was that for the men, with exception of Stephen and Alan where they did not have a choice whether to attend their GP, there was a delay between the age of onset and the seeking of help. Research evidence to date is not clear on the average time it takes men to seek help. Paterson, (2007) suggested it took on average six years, which was questioned by Jones and Morgan (2010) as being too high. The men in this study were asked how long they thought they were ill for before seeking help. It would appear however that the most common time period from the narratives was their ED behaviours started around the age of 15 and help was first sought at university, around the age of 18. This would give a time period of around three years of symptoms before first engagement with health services. These men also shared a similar narrative whereby they were able to exercise some control of their ED at home, but university allowed them to be in full control of their eating behaviour, to the point where the symptoms escalated or reappeared. However, the longest time span from first ED behaviours to actually accessing help was Kevin who had symptoms and episodes over approximately 15 years. It must also be noted that the symptoms and effects of EDs are not immediately apparent and there will be a delay in onset which will differ from person to person, with factors including starting weight, amount of restriction, exercise and/or purging, social isolation, all impacting on the severity of the illness.

With the exception of Richard (who collapsed and was rushed to hospital) all of the men went to see their GPs. All had realised that something was wrong, reporting being unable to function in their day to day lives. Both Alan and Stephen were under 16 at their first interaction with the health services; Stephen was taken to his doctors, by his parents, for Alan it is unclear who actually went with him, if anyone, stating that his mother booked his appointment, but she did not go with him as she was initially angry and upset. However, all of the men who saw their GP were referred to counselling or directly to an ED specialist service, the actual service they received and the waiting times were dependent on their geographical area.
Not all of the men shared how long it took from referral to treatment. Of those who did, Alan spoke of living in a rural area and that he was offered what appeared to be general counselling based within his GP’s surgery. He had to wait two years to see a specialist ED CBT therapist, and within this time period he was taken to see a private therapist. Stephen waited ten months to see a special CBT therapist. Michael on the other hand, was within the catchment area of a trust with a specialist ED service, and was seen within three months. Kevin believed he waited between three and four months before seeing a specialist service and be officially diagnosed with an ED.

12.4.2 - GPS ON THE FRONT LINE

Some researchers (Paterson, 2004; Soban, 2006; Brown, 2007) have highlighted GPs often not recognising ED symptoms within men. It would seem from the narratives presented in this thesis that the majority of the men’s first encounters with their GPs were positive in terms of being taken seriously. Only within Kevin’s narrative could it be construed that his GP may have looked at alternative answers to explain the symptoms he was reporting. Kevin commented that his GP looked “non-plus[ed]” (Kevin Line 60) when he spoke of his symptoms, and his first action was to administer Kevin with tests for depression and then refer him to a community mental health team. He was later referred by the mental health team to a specialist ED service. This is a tenuous point as the referral protocol is not known for the area Kevin was treated in and his GP may have been following protocol rather than, as Kevin may have thought, not understanding his symptoms.

Russell reported a poor experience with his GP after his initial diagnosis in an episode which is difficult to interpret. After bone density scans, Russell was advised by his GP to take up running, this advice being contrary to the advice he received from his nutritionist who stopped him engaging in exercise. Russell spoke of not understanding what he was supposed to do, as he knew exercise was harmful, but his GP was recommending this. For Russell, there was a total disconnect of services and he decided to not use the NHS and went down the path of private health care. So being fair to his GP, he may have issued general advice, but this does indicate a lack of understanding of Russell’s relationship with exercise and a disconnect between the parties treating him.
12.4.3 - OUTPATIENT TREATMENT

12.4.3.1 - Counselling

The men had different experiences of therapy as they were at different stages of their lives. Alan, Henry, Stephen and Michael had multiple treatment episodes. Richard was not able because of his gender, to get NHS therapy, and had to make do with some generic treatment through his university. However, he felt that this was not useful. At the time of their interviews, both Russell and Kevin were experiencing their first exposure to treatment and, as such, could not comment on long term effects or its potential success. The sub-theme which came from the men’s stories about their counselling experiences was that there was no concrete answer to which particular approach to counselling was best; and perhaps the best predictor of success in therapy is the person’s own desire to get well. This is in keeping with other research (Goldman et al., 2016).

Henry, Michael and Alan shared that their ED behaviours were not totally eradicated after counselling. Both Henry and Michael were later treated as inpatients. Michael stated that it was decided therapy was not working for him and he needed to be admitted to hospital. He later had more therapy and inpatient treatment. Alan spoke of multiple episodes of his ED behaviour. He was at first given general counselling and then after a period of time CBT. After completing his CBT, Alan said that his ED behaviours still continued linking them to stress. However, Alan believed CBT therapy to be “100% CBT is the way forward.” (Alan Line 326) and thought this should be the first line of treatment for EDs. Indeed, CBT is one of the recommend treatments by N.I.C.E (2004). However, Alan also commented that he felt "panicky” (Alan Line 335), as, after a two year wait for his CBT treatment, he only had thirteen sessions in essence to get better. He was told that once he had finished treatment he would have to go to the back of the queue if he needed further help. Stephen stated that he felt his CBT was beneficial because he wanted to get better. However, even after his therapy, Stephen indicated that while he no longer restricted his food intake, as he had previously done, he was still socially isolated and lacking confidence (indicating his underlying problems still existed). Stephen felt that as he got older the treatment he needed for his ED and its effects was more difficult to access. He also felt that people would be put off by the long waiting lists for specialist treatment.
Russell had a very different experience of therapy, as he rejected NHS treatment before any sessions began, falling out/losing trust with his local mental health team. This was due to him asking for his first session to be at his home and the practitioners arriving early and being told this was done to show him that he was not in control. As a result, he chose his own therapist and style of therapy.

12.4.3.2 - Dieticians/Nutritionists

Three of the men, as part of their treatment saw dieticians. The three men Russell, Alan and Henry all found the same problem with this process. In essence, the dietician/nutritionist was almost expecting to work with someone who both physically and mentally wanted to eat and therefore provided general information on what to eat and when, but not on how to actually eat or to work with the men’s individual issues. Alan went to one session and stated he felt the dietician to be patronising and not helpful, because the information given was what he already knew. Henry commented on experiencing dieticians during inpatient treatment, suggesting because others were controlling his food and making him eat, it had a positive effect. But as soon as he was in the outside world, knowing what he should eat did not make him able to do so. Russell, taking charge of his own treatment, dismissed his nutritionist, as he did not have a good relationship with her and secondly because he felt that she was not scientific enough.

There were times that she would talk to you, if you could imagine going weeeeee here comes the aeroplane as the spoon comes towards your mouth and I thought ‘you have completely misunderstood me completely’ and we just did not get on. I called her a tree hugging hippy. I come from a slightly scientific background that I like to know why, and I ended up having quite a heated argument. (Russell Line 915-19)

The whole area of dieticians/nutritionists is interesting; within treatment the importance placed on weight gain (boosting mental and physical well-being) makes the dietician/nutritionist a very important member of the healthcare team. Cockfield and Philpot (2009) stated this, but also added there is “paucity of research on nutritional interventions in anorexia nervosa” (p. 84), calling for greater research in this area. The testimonies of the men in this study who had experienced such treatment would also indicate that more understanding is needed in this particular area, especially where there is a requirement to develop therapeutic relationships.
**12.4.4 - INPATIENT TREATMENT: HOLIDAY HOME VS PRISON CAMP**

Only two of the men experienced inpatient treatment in an ED specific unit. Interestingly Henry felt it was “like a prison” (Henry Line 254) whereby he suffered a “loss of liberty” (Henry Line 254) and his freedom to make decisions was taken away. Conversely, Michael enjoyed the absence of responsibility. This contrast in opinions was found in the research of Colton and Pistrang (2004), albeit in their female only adolescent sample. Henry did not like being on a ward with other people with EDs, and although he did not say why, he did state being on a unit was “the worst experience of my life ever” (Henry Line 250).

However, Colton and Pistrang (2004) found that whereas some people find solidarity with people in a similar situation, others may become more competitive (in their ED behaviours) or find the distress of others hard to cope with. As stated previously, Henry did not like being an inpatient, but Michael found a sense of belonging as he was not isolated, but with people who shared similar experiences. Henry did find isolation was a problem during his inpatient stay as he was approximately 50 miles from home which put a strain upon his family when visiting, and he did not build any relationships with people within the unit.

Michael had two separate sojourns within in-patient units, in different parts of the country. One of the reasons he felt that his first stay was not successful was that there was a focus on weight gain rather than on him and the staff looking at his inner problems. Whilst he enjoyed his sojourn it did not stop his ED behaviours long term. The importance of addressing the individual emotional needs of those receiving inpatient care for EDs, has been consistently identified in the literature (Button and Warren, 2001; Colton and Pistrang, 2004). Whilst Henry had nothing but scorn for his inpatient treatment, he did say that when he began to feel as if he could get somewhere with a therapist he was discharged. It could be assumed that the reason for his discharge at this point in time was he had reached a target weight. Button and Warren (2001) noted that health services must “extend [treatment] well beyond weight restoration and recognize that these are very vulnerable people, who often have long-term low self-esteem and problems in coping with life and their relationships with others” (p. 94). In contrast, it has been noted that in-patient treatment is not for everyone, some will embrace it and others will not (Colton and Pistrang, 2004). This was illustrated in this study; Henry hated it with his alluding to it as
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12.4.5 - SECOND CLASS CITIZENS, GENDER ISSUES IN TREATMENT

James Brown may have sung about this being a ‘Man’s World’, but from some of the experiences of the men interviewed, within the world of EDs it most definitely is not. The men spoke about how they felt that they were marginalised by female stereotypes, there being a lack of information on male EDs, gender biased treatment and classifications. Such examples of inequality give rise to consider if these roles were reversed would there be a much greater cry for ‘equality’.

Stigma created for men because EDs are primarily viewed as female illnesses has been documented (Raevuori et al., 2008; Jones and Morgan, 2010). Jones and Morgan (2010) suggest stigma is not just confined to health care writing; the stigma for men with EDs will continue as long as clinician’s focus upon a framework of physical, psychological and emotional help based upon women. These sentiments were clearly paralleled by Henry’s interpretation of his experiences of treatment. He felt that ED stereotyping was reinforced by staff during his inpatient care. He stated that he found his inpatient treatment “condescending and patronising” (Henry Line 266), and held similar opinions of his outpatient care, commenting on the use of female specific examples during his therapy. Kevin had what can be described as a similar experience. Kevin explained how during a group therapy session on self-care, the therapist gave examples to the group of moisturising or doing their nails, saying to Kevin, “but you don’t need to worry about that kind of thing!” (Kevin Additional Email Lines 20-21). Kevin responded “I made a joke at the time…. but underneath I did get the message that, as a bloke, self-care was not something I should be interested in, which is clearly bollocks” (Kevin Additional Email Lines 21-23). In no way, shape or form did Kevin suggest, or it is suggested here, that this was anything but Kevin indicating that this was the therapist making a joke, but it put him in an embarrassing position and potentially reinforced gender differences between him and his fellow patients. It also gave out a stereotypical message that it is only females who

prison, where as Michael said he; “really enjoyed It, loved being the only man on the unit got all this female attention for pretty much for the first time in my life” (Michael Lines 815-17). Henry commented that he had erased the name of the unit from his mind, but it was not clear if he was joking or was operating a form of psychological repression/denial.
should worry about self-care. Whilst innocuous, even the most innocent comment can hurt, especially when someone is experiencing mental health difficulties.

Kevin’s and Henry’s views were further reinforced by Michael, who felt that at times he was unable to relate to his treatment, and Stephen who felt he could not share his thoughts during group therapy as he was the only male. These concerns were echoed by Robinson et al. (2012) who commented that the only male in the study had spoken of being excluded from treatment groups due to his gender and feeling that stereotypes were transposed onto him, which he felt were not a driving factor for him.

Kevin also encountered physical stereotyping. As the only male on a day patient unit he had to use the disabled toilet because there were no facilities for men, only for women and the disabled. This leads to questions over the planning and construction of the unit whereby men, it could be suggested, were presumably overlooked because only women get EDs. Kevin’s experiences of stereotyping were not limited to his actual treatment, encountering gender stereotyping previous to this beginning. Kevin found that in letters from the ED unit to his GP, he was referred to using female pronouns. Kevin felt that even though this may have been a simple clerical error using a standard letter template it; “was annoying at the time, mainly because it betrayed a lack of care or attention, but I suspect part of why it has stuck with me a couple years later was that it reinforced the fact that I was abnormal” (Kevin Additional Email Lines 13-15). Statistically it is clear, more females are treated as inpatients with anorexia and a-typical anorexia than men, with statistics from England showing 93% female, 7% male (N.H.S Digital, 2013). Whilst in wider society female ED stereotypes have to a certain degree be accepted and understood, however from the context of treatment providers it is disrespectful, emasculating and unprofessional. Such errors can be problematic as the general public cannot expect to be aware and respectful of male EDs when health authorities make such mistakes as to assume that every person in treatment is female.

Stephen experienced gender bias when his ED was first diagnosed; this was before the updating of the DSM V and was classified as EDNOS because his BMI was not low enough for a diagnosis of anorexia. This is a barrier to treatment for men consistently identified in the literature (Duker and Slade, 2003; Treasure, 2005; Peat et al., 2008; Ousley et al., 2008). The question of the use of BMI as a gauge of seriousness is
problematic in men. Stephen exemplified this because he reported problems with the pitch of his voice, affecting his day to day life, and was having speech therapy for this into his twenties. This potentially indicates delayed puberty (Koenig et al. 1977), and as such would indicate potential malnutrition. It appears that Richard had a similar problem to Stephen in terms of his BMI being used as a tool for people to get treatment. Richard’s treatment journey was very different from the other men. Firstly, Richard did not go to his GP, but collapsed and was rushed into hospital with gall bladder and pancreatic problems caused by his weight loss. Secondly, although being diagnosed with an ED on admission to hospital, Richard did not receive any psychological treatment for it and had to self-refer when discharged after a number of months of inpatient treatment for his gall bladder and pancreas problems. When he self-referred he was not deemed ‘ill enough’ and to date never received treatment from the NHS for his ED. Richard said that he was told that he could not get help because his local ED service was inundated with females and because he was male he had to wait longer. “I was refused because I was a male and they had lots of females coming through. There was such a shortage of beds, despite the fact I was classed as nearly dead” (Appendix 11 - Richard Lines 252-53). Although speculation, it is possible that Richard’s ‘rejection’ was because when first seen by his local ED service he could not satisfy the needed BMI calculations; this fits with Stephen’s experience and that of other research findings (Duker and Slade, 2003; Treasure, 2005; Peat et al., 2008; Ousley et al., 2008). It is possible that in the time from Richard’s admission to hospital to leaving, he put on enough weight to not be deemed a serious case when being assessed. The justification of this supposition is taken from Colton and Pistrang’s (2004) findings, and Henry and Michael, who both received inpatient treatment for their EDs, all of whom commented on the focus on gaining weight as opposed to examining the underlying issues. Although, given Richard’s account, this does not explain his lack of referral for treatment whilst in hospital after being diagnosed on admission. The theme of BMI caused Henry to pass comment on BMI being “an incentive for people to make themselves even sicker to get the help they need!” (Henry Lines 805-06)

12.4.6 - POSITIVE WORKING RELATIONSHIPS AND THE WILL TO GET BETTER

It is very difficult to interpret the men’s experiences of counselling or treatment as they were subjected to different approaches and styles. A sub theme which became apparent
was the need for a positive and respectful relationship to exist between all parties. Alan’s initial therapy sessions (whilst waiting for specialist CBT at his nearest ED centre) were not successful and were stopped by Alan as he felt that the therapist was patronising. He felt he had better results with a therapist organised through his college, whom he had a better relationship with. Henry commented upon his therapy improving when he was paired with a “particularly good psychologist” (Henry Line 261). Michael spoke of a “therapist who was outstandingly brilliant” (Lines 847-48) who helped him, after twelve years, to face his underlying issues rather than focusing on controlling his weight.

The therapeutic relationships should encompass mutual respect, whilst at the same time recognising boundaries between therapist and patient (Goldman et al., 2016) but good relations seem to be a positive (Rayner & Warne, 2016). This was not the case for Russell, whose narrative exemplified how he went from a much more open and friendly nutritionist, who responded to his emails out of session, to having much better results and relationship with a dietician who was much more bounded in her relationship with him. Russell felt that this was helpful as it offered him much more structure. It was apparent from Russell’s narrative that his life was very structured and rigid, especially in relation to food and exercise, this trait being noted in other research findings (Murray et al., 2014).

Broadening this theme to control, Russell, because of his rejection of the NHS, employed his own therapist. He spoke of investigating and researching local therapists. This he felt was beneficial as he selected someone with whom he felt he could relate, rather than having a therapist foisted on to him. Although subjective, the men’s opinions of therapeutic relationships do correspond with the findings of others (Button and Warren, 2001) who conducted a study based on qualitative opinions of ED health care.

Whilst the men stressed the importance of a good therapist, it must also be noted that a number of them stated the importance of their own positive thinking. Stephen said “I had cognitive behavioural therapy which I found helpful, but only as I wanted to recover.” (Stephen Lines 41-42). Michael said “it doesn’t matter how many wonderful therapists you’ve got and how many wonderful plans that are set out … if you really don’t go for it, it won’t work in the long term” (Michael Lines 911-15). Henry who was quite disparaging about his treatment experiences, agreed in a roundabout way with the other two men’s opinions saying; “that’s a problem especially as you've got to buy into treatment as it were,
got to commit yourself to it and it kind of makes you feel like ‘I’m buying into something that doesn’t quite relate to me.’” (Henry Lines 295-97).

12.4.7 - SEARCHING FOR HELP: THE ROLE OF ED CHARITIES

Asking the men who took part in the study about their experiences with ED charities was interesting, the men offering their reflections of their experiences seeking help and information, and of trying to raise awareness of EDs in the wider community. It was surprising that as a group, despite a number of men being active within fund/awareness raising, the overarching emotion was one of disappointment. Whilst there are a number of ED charities in the U.K., the interviewees only focused upon two, Beat and Men Get Eating Disorders Too (MENGET). All of the men became participants of the study through the charity Beat who advertised the study on their website and social media pages, as well as contacting men they have on a database who wish to help in research studies on EDs. Therefore, the men all knew Beat as the primary ED charity in the U.K. The men were also aware of MENGET, perhaps because it the most high-profile male specific ED charity in the U.K. The fact that all of the men participated in the study via Beat is an important point to make considering some of the negative themes, stemming from the men’s narratives, not least of which was that a number of the men were dissatisfied with the organisation even though they engaged with the charity’s work.

12.4.7.1 - Beat - The Good, the Bad and the Ugly

Alan felt that the charity made a positive impression in the areas of research and publications, but it faltered in raising day to day awareness of EDs. Henry and Michael believed Beat did good work and Stephen commented on its role being important in raising awareness and education. However, Henry said his overriding opinion was one of dissatisfaction.

A number of the men including Alan, Henry, Kevin, Richard and Russell made comments about the charities interface with the public. The main comments related to the charity being very stereotypically female focused, with the stories that the charity promoted being those of younger female survivors. In short, the men participating in this research felt left out and more stigmatised. This was disappointing as Cooperman (2000) in her research for
the Eating Disorders Association, now know, as Beat recommended, they “need greater publicity about men with eating disorders and to highlight this issue” (p 19).

Richard felt that even the colouring used on the website was geared more towards a female clientele rather than being gender neutral (please note Beat’s website was redeveloped between Richard’s interview and this publication). Not using gender neutral colours was in contrast to research findings which suggest to better help men there needs to be more gender-neutral campaigning (Mitchison et al., 2013). However, Kevin commented that he could understand the charity’s bias towards females, as the statistics relating to males with EDs are low in comparison to younger females.

Some of the men had specific experiences of how they felt let down by the charity, notably how they believed it was geared towards raising money over helping people. Russell spoke of wanting to take part in a fun run to raise money for the charity and being told by Beat that they could offer him some support such as a vest, but he would have to donate first to get one. This could be an example of why trust in charities has decreased in recent years, due to more pressure and direct fund-raising attempts (Charity Commission, 2016). Russell felt this promoted the corporate side of the charity, which he believed was reinforced by their website, giving the impression the charity employs people pursuing a career rather than having an interest in EDs.

Alan commented on a link the charity had with the outsized clothing retailer Jackamo to sell charity socks on-line. Alan felt that with the connotations of EDs, and specifically anorexia, it was in bad taste to link with this particular retailer, as the likelihood of people with body image concerns, might have issues being directed to a site known to cater for larger people. Alan’s concern can be linked to Russell’s comments regarding corporateness; actions being taken for something making corporate sense (i.e. making use of a well-known retailer) to raise money, rather than thinking about the target audience.

Richard was quite vocal in his criticism of Beat calling the charity a “money whore” (Richard, Line 803), alluding to what he felt was the charity’s money raising abilities and focus, and which he believed was not disseminated correctly. The transparency (how donations are spent and/or are tied up with corporate organisations) and spending on administration of charities were identified by the Charity Commission (2016) as major factors in a lack of public trust.
Alan had a further negative experience of Beat, which he said, organised an interview for him with a national media provider to talk about his ED. The interviewer asked him about his weight and when he refused to comment on this, Alan believed the interviewer turned on him. Alan reported that he never received an apology from the interviewer or Beat, and in his opinion, Beat had not been clear with the interviewer what the boundaries of the interview were, despite their media guidelines. Alan felt let down and unprotected by this experience.

A number of the men spoke about poor experiences of giving media interviews (radio, newspapers and magazines). Whilst it is not clear how many, except for Alan’s, were set up by Beat, the overall experiences of the men were poor, with them feeling they were generally only being used to create sensationalist stories and when they tried to control the narrative, media providers did not want to know. This is an area of concern with Murphy et al. (2013) showing the continuing stigma of mental illness via the media and a lack of adherance to, or knowldege of, Beat’s guidelines.

12.4.7.2 - MENGET – The Good, the Bad and the Ugly

Alan, Stephen and Michael were happy with MENGET and the work the charity does, which in some ways is unsurprising due to the charity’s goal to raise awareness specifically in the field of male EDs. Russell was effusive in speaking about how he felt he could identify with MENGET rather than Beat, and this reaction was borne out in the research. Breeze (2010) suggested people often support organisations which promote their personal preference, help those they have some affinity with and adopt causes related to their own life experiences. Russell felt MENGET was more personal and he could see that people within the organisation had experiences of EDs and were not employees, as he felt with Beat, which perhaps demonstrates the importance of non-economic or soft factors in trusting a charity (Yang et al., 2014).

However, the charity’s reach was highlighted by a number of men (Kevin, Michael and Richard) and for a ‘national or main charity’ this theme needs to be given due consideration regarding the ability of the charity to meet the needs of men nationwide. Richard believed, when taking account of the money the charity received, it did not do a good enough job outside of the South East of the country. Richard was extremely critical of the charity and felt that some of the people who were prominent in the charity were
getting too much personal exposure, almost using MENGET as a vehicle for self-promotion. This was an extremely forthright opinion; however, of the men interviewed, Richard was perhaps best placed in terms of knowledge of the ED charities and the charity sector from his experiences, so it should not be discounted as ill informed.

12.4.7.3 - Seeing the Bigger Picture

Both ED charities could make legitimate comments which explain away the comments made by the men in this study, with interviews taking place in 2015, much work may have been done such as Beat’s new website. However, trust and confidence in charities as a whole has declined, with a “significant decrease”, and being at its lowest level since reporting began in 2005 (Charity Commission 2016, p. 4). In addition, the good work of smaller charities (raising under £100,000 a year) was reported as being overshadowed by the work of the larger charities who; “are the focus of suspicion from those who are most cynical about the motives and efficacy of charities” (p. 8). Regardless of the perceived negative and positive aspects of the charities, a major theme which emerged from the narratives of the men was the timing of when they engaged with such services. It appeared the men did not engage with the charities until after diagnosis. This was largely due to the men not being aware of the possibility of an ED as an explanation for their poor health. This would indicate a failing on the part of charities and other health providers in attempting to increase awareness of EDs pre-diagnosis. Kevin echoed the sentiments expressed by the majority of the men when he said; “I am aware of Beat, I am aware of Men Get Eating Disorders Too. I became aware by having one [ED], and googling.” (Kevin Lines 459-60).

12.5 – REVIEWING THE EXTRACTED THEMES

The themes drawn from interviews are of course subjective and a different researcher may have focused upon different areas. What they do show (re-examining John Doe, masculinity, employment and help experiences) is that the original premise of this research to gain a broad understanding of men’s experiences of EDs has been successful and each one of the themes could and should be examined in future research in greater detail. Re-examining the John Doe anorexic showed that, broadly speaking, the men within the study
shared many traits and experiences with men from other studies, which adds to the validity, trustworthiness and authenticity of this study and that of the men’s stories.

The examination of masculinity showed that it is an extremely complex topic; the men seemed to have different ideas surrounding masculinity, indicating the global, regional and local levels indicated by Connell and Messerschmidt, (2005). The difference in sexual functioning between the gay men and heterosexual men was a very interesting outcome from the narratives, appearing to indicate that a breakdown of masculinity may be more of a burden in heterosexual men than gay men. This is due to the increased isolation in the straight men as opposed to the sexual activity which weight loss brought to the gay men at different points in their ED.

The examination of employment issues was important and the men’s narrative vindicated the topic’s inclusion. There was clearly an impact on a number of the men’s working lives, from only working part time, changing careers or putting them on hold. Questions were raised about capacity to work with mental and physical health issues in caring/responsible professions. It was clear that a number of men had worries over disclosure and their thoughts on the potential reactions of employers. Broadly speaking, those men who disclosed did not have any major issues to report in terms of the employers. The only exception was Kevin who, it could be argued, had a negative reaction with his employer appearing to put more pressure on him. This was quite startling given Kevin’s role and the size and nature of his employer.

The final theme taken from the narratives was the men’s experiences of seeking help and treatment. There were differing stories, some men seemed to have had much more and quicker treatment than others who were rejected. Whether this due to the severity of the illness or geographical reasons is open to conjecture. However, in the case of Richard who was admitted to hospital with severe problems due to the breakdown of his health from his ED, it does appear baffling that he never received specialist ED care. The men were all asked about their experiences of ED charities. Surprisingly, given they were recruited from social media adverts from one of the charities, the overall opinions were negative. This poses a number of questions about how ED charities try to raise awareness of EDs in men, how they should market and present information and, given some of the men’s treatment experiences, how they could be advocates to help reduce gender bias.
CHAPTER 13 - LIMITATIONS, LAMENTATIONS AND LEARNING

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons
13.1 – OVERVIEW

Only the most egotistical of people would not recognise the value of self-reflection within life. No piece of academic work is complete without honest reflection on the processes used to gather, process and present information. It is fair to say that nearing the end of this PhD project if a ‘rewind button’ was available this work would look very different. That is not to say, in no way, shape or form is this work and what it represents not worthwhile, as a piece of academic research or a learning experience on both a professional and personal level. So much has been learnt whilst researching, and on reflection, the processes used to get to this point seem rather rustic and if repeated could be tidied up and made much more efficient. This, of course, is the benefit of experience and the confidence it brings, from thinking that a point thought unachievable is actually real.

This section examines my own personal thoughts and processes about where I believe I could have improved my work, some of the issues I faced, and in some cases the justification of why some decisions were made when the reader may feel a different course might have been steered.

This section includes the following,

- The challenge of changing supervisors.
- Allowing the participants to choose their own interview method.
- Using a theoretical sample that was not necessarily reflective.
- The question of co-construction within interviews.
- Bias and remaining as objective as possible despite my history.

13.2 – REFLECTING UPON MY INTERVIEW EXPERIENCES

I believe I was fortunate in that I was able to experience face to face, phone and email interviews whilst collecting the men’s experiences. In hindsight, and which may seem to contradict the previous sentence, I would have preferred all of the interviews to have been face to face because I felt more able to represent emotions when able to look and listen to the participant, than listening alone. However, I believe that I was fortunate, as the
learning gained from experiencing the different forms of interviews was invaluable at such an early stage in my development as a researcher.

Chronologically, the first interview conducted was face to face with Henry. If anything, this was the best start possible. Even before the interview had started, when I shook Henry’s hand outside the venue and he took mine in both of his, I quickly realised the honour that was being bestowed upon me of being allowed to listen to his story (and consequently the other men’s stories). As his interview progressed, the responsibility of having to present his story as accurately as I could became clear. The study in some ways shifted from me wanting to make sense of my own experiences, to present other men’s stories too and to try and help them. This was an extremely helpful motivator during the many times I questioned my ability to succeed. The message in my head was that the men were relying upon me to tell their stories.

Whilst using the interviews as a motivator, there was no doubt that listening to the men’s stories also had some negative effects, so much of what was said was akin to my own experiences and it did cause moments of depression and personal reflection which had to be worked through. This once again reaffirmed my belief that 100% objectivity does not exist and that the nature of developing as a person involves the risk of challenging yourself and leaving your comfort zone.

Initially there was no doubt that I was not prepared for the openness which I encountered. It had taken me a number of years of CBT before, to my acute embarrassment, I spoke to my therapist of personal issues. In light of this I did not expect the men would want to tell a complete stranger intimate thoughts/experiences, but they did and the tapes and transcript clearly show that if anyone was embarrassed it was me in the apologetic way questions were asked. As the interviews progressed I felt more at ease, perhaps a little too much, as when Richard, in the last interview shared that he had been raped, I almost missed it.

Although the interviews followed a semi structured path based around some thematic questions and then follow up questions, the participants were asked at the end if they wished to add anything to the discussion. Responses to this suggested that the themes selected had been worthwhile. This was personally satisfying, because I felt that incorporating a section based upon employment, an area I felt that other studies had ignored, and which my own personal experiences told me I should investigate, was a risk.
No one can question that the men’s stories all show experiences of varying problems at work, whether from an inability to do a job, work full time, to ambiguous reactions from employers.

Perhaps my biggest surprise was that the interviews made me feel less isolated as a person, and whilst I cannot turn the clock back and not experience what I personally did, the men’s stories made me feel less alone and different. For example, some of my treatment experiences were replicated in their stories and I was able to empathise with what the men were saying. My parents had a poor experience with the charity Beat. When they phoned up for help they were sent a magazine and a list of books which they could buy from Beat, and this affected my viewpoint of the charity. It was therefore unfortunate that, although the men saw the value in the charity, they were very critical of it. However, moments like this provide a personal benefit that “it’s not just me”, but also infuriates, because whilst life cannot be perfect, the men seemed to repeat stories of failings which are familiar, and while if reiterated by one person you can suggest it may have been a random occurrence, a number of stories of unrelated people making similar criticisms seems to be less coincidental and more institutional.

As the stories progressed, the shared experiences mounted. A critic could point out that there would be shared experiences when all the men were asked about the same themes. However, the men generally experienced problems in treatment, and their backgrounds in one way or another fitted into the information gathered in the literature review. As this information mounted as the interviews progressed, it did make me feel that the work was worth it, especially when hearing a number of men lament the lack of research asking them for their thoughts, experiences and opinions.

13.3 – THE MISSED THEME?

Reviewing the men’s stories brought out four main themes, which were identified and discussed. However, the question of gender, gender discrimination and in some case societal gender hypocrisy were sub themes which crossed over the themes. I did consider if this should be a separate theme and this was discounted because I largely felt that it may draw criticism and accusations of being sexist/patriarchal for both myself and the men. As such, I put the men’s experiences within the themes they were talking about.
In hindsight I would probably lean toward the conservative path taken as the best course because I did not feel that enough detail was gathered to rationalise above the level of speculation. However, this I feel is an important area which needs further investigation and not just within EDs.

13.4 – CO-CONSTRUCTION

The question of co-construction was discussed within the Section 3.4.5.1.1, even though the decision to not co-construct was justified, it could also be as argued a limitation of this study. Would co-construction have made this study better? The answer is both yes and no. Co-construction would have made the analysis of the men’s stories much easier and may have given a richer depth to the men’s data, as they would have had an opportunity to reflect upon their words. While this could have been useful, stories are temporal and therefore revisiting them may not necessarily add to the richness of data, but rather produce a different story (McAndrew, 2008). However, in order to do this I would have had to reduce the number of interviews because of time constraints. My belief at the time of methodological construction and with the benefit of hindsight, presenting the stories of seven men in this thesis is much more preferable to presenting three or four co-constructed stories. This was an exploratory piece of research, and as such the aim was to in some ways fill in an outline of a research map which others who follow can fill in and detail.

Although I feel the correct decision was taken, it does worry that many of the men wished to see the final study. There is the possibility they may feel upset if the interpretation of their stories does not fit with their own views. I know from my own personal experience how this can hurt. Co-construction is perhaps a topic for a series of research papers, whereby the men’s stories can be re-written with their input.

13.5 – KEEPING DISTANCE, BUT HEARING THEIR VOICES

There is debate regarding who is best placed to undertake research with sensitive topics such as this; a person who has experienced an ED and who has experienced life changing events in part due to it, or someone who is detached. Wright and O’Toole (2006) presented research where they asked ED professionals if they felt ex-patients had a place in health
care delivery, 70% of respondents felt that they did have a place. However, the question of bias and subjectivity is a legitimate one.

With a researcher with a history of EDs and, at the start of the research, still engaged in CBT, interviewing men with a history of EDs about EDs, questions about subjectivity was (via supervisory meetings) and is a constant topic within this study. In keeping with the epistemological position of qualitative research and the acceptance as human beings we cannot divorce ourselves from our own backgrounds and feelings, subjectivity is integral to the process of study. Subjectivity has to be accepted as real and the same information, as presented in this study, will be interpreted in different ways by different readers.

I cannot hide from the fact that my experiences of treatment and trying to work with an ED are the reason why this document exists. Simplistically, if I had been able to access treatment, I would not have deteriorated mentally as I did, and if I had been able to manage the pressure of work, I would still have been teaching and therefore would not have the time to seek answers and to try and improve my education. What I have tried to present are the voices of the men and not my own personal constructions based on my experiences or even my own bias. I feel that this has been completed successfully, but I recognise that the reader may question this and as such this is a limitation of the research. However, I would argue that all researchers must have some form of personal interest in their work.

Accepting that subjectivity exists and personal opinions/experiences can influence outcomes is one thing, but in order to produce a legitimate piece of academic work, it was important to try and negate any challenges to authenticity; this was done through the methodology. The interviews were based around the evidence provided in literature review and introduction. All of the men’s analysis was examined by the supervisory team and questions posed were then discussed and challenged within supervisory meetings. Further to this, individual analysis of each story was undertaken and reported on, followed by these being compared and contrasted and themes compiled which formed the basis of Chapter 12, as well as the conclusion/recommendations. It is also worth noting that as a business (B.Ed. (Hons) and MSc), and not mental health specialist, I was aware of my limitations and my own naivety as an outsider in the subject area. This I believe helped to ameliorate any preconceptions, allowing me to ask for and use the experience and guidance of my supervisors (both mental health experts) to frame the analysis. However,
While all attempts were made to reduce subjective bias, it remains inherent in parts of the study. While having experienced an ED may lead to concerns about my subjectivity, it must also be said that in some aspects of the study it was beneficial. It allowed real empathy to be shown to the men during the interviews. It may have also helped them feel more at ease as during the introduction it was explained to them that I had had an ED, hence the reason why the study was taking place.

### 13.6 – THE CHALLENGE OF ACCOMMODATION

With such a small potential sample, efforts were made to accommodate each potential participant (and not lose them) by asking them to choose an interview method which they were most comfortable with. This resulted in one man (Henry) asking for a face to face interview, one man (Stephen) asking for an email interview and the rest asking for phone interviews. Using three different interview methods was, from a learning experience very good, as each have their benefits and challenges. It can be suggested that using different interview techniques could compromise the data analysis. For the face to face interview visual clues could be noted/interpreted, this is not available during a phone interview where only the respondent’s words and intonation of his voice can be heard and interpreted. With an email interview neither of these are available, interpretation is solely based on the written answer. The email interview with Stephen raised a number of questions, but Stephen made it clear that he did not want to meet face to face, nor participate in a phone interview. Initially I was quite happy with this; as a researcher it allowed me to experience another form of data gathering and secondly it would negate the need for the time and expense that would have been incurred in obtaining face to face/phone data through transcribing.

Stephen was sent a list of questions based around the study’s themes which formed the basis of all the interviews conducted up to that point, and he was asked to comment on them. He was sent, on two occasions; follow up questions to expand upon his previous answers, mimicking the flow of a verbal interview. Stephen usually replied within 24 hours of any emails, which showed a keenness to take part. However, this keenness to take part was contrasted by a lack of depth in his answers and was the biggest imponderable in his narrative, raising question regarding the feasibility of email interviewing. Whilst I did
think, with enough repeat questions, Stephen may have shared a lot more, but the time in
doing this was a factor that could not be ignored and I decided to end the interview after
three sets of questions. As time progressed and Stephen responded it became clear that this
was not the ideal medium to get the information desired for this study as the depth of his
answers left many questions unanswered. However, and being pragmatic, if this was the
only way Stephen would participate then it was best to get his limited narrative than no
narrative at all. It must be stated that two of the men used email to share additional
information after the interview. This worked well as it allowed them to think about their
thoughts and add depth to their interviews. For me this indicated that although my
experience with Stephen may not have been ideal there is still merit in the medium.

On reflection I do not feel that offering the men a choice of interview was a limitation,
even if different methods offer more depth than others. Before each man’s story it was
clearly identified how the information was gathered and the reader is free to form their
own opinions as to trustworthiness of each interview. Further to this was my interpretation
of the ethical considerations for participants within research. Namely the researcher’s role
to provide an environment/setting/condition which is comfortable to the participants,
therefore giving them the choice seemed to me to be the best course of action. However, I
personally took part in two recent studies, one ED related and one about Brexit, whereby
my desire to give information visually (face to face in one and via video link in another)
was rejected by the researcher. Although I still took part in them it did make me feel a little
unsure as to who was supposed to be comfortable.

**13.7 – A SAMPLE OF ACTIVISTS**

The study could not have taken place without the men who took part giving up their time
to share their stories with a complete stranger. However, all of the men who took part had,
or had tried to access health services, and it would have been beneficial to hear from men
who had not sought professional help. A number of the men were also active in promoting
awareness in males EDs through charity work, sharing stories in the media and even
publishing their own story. All of the men accessed either Beat’s website or their social
media applications. As such their stories need to be taken in context as men who have
taken steps to recover. A number of studies from the literature reviewed noted the
limitation of having a narrow sample (Strober et al., 2001; Lindblad, et al., 2006; Mehler et al., 2008; Gueguen et al., 2012; Núñez-Navarro et al., 2012; Murray et al., 2014). This could be construed as a limitation of this study, which I felt was valid, whereby the process of recruitment only allowed for men who had taken steps to get treatment to participate, indicating that the sample did not consist of any men who had not engaged with the health services, albeit NHS, private or third sector voluntary organisations.

13.8 – THANKS, BUT NO THANKS

One of the most difficult decisions that had to be made was to not present the story of Martin (who was bulimic) within this thesis. The reason for not including his story was, as the only man in the study with such a diagnosis and the focus of the study being on anorexia and forms of a-typical anorexia, it is likely it would have introduced different dynamics and made the generating of themes from across the interviews difficult. Ironically, Martin’s interview was the longest and his story took the longest time to analyse. In hindsight it would have been a more efficient use of time to have not interviewed him in the first place. However, he took the time to access the study and was keen to take part and share his story. I did not want to make him feel unwanted and also felt that his story may be useful, especially if more bulimic men asked to be interviewed or as a contrast to the anorexic men’s experiences. This perhaps highlights my naivety as a researcher, worrying about how many participants I would attract to the study and not wanting to refuse anyone. During the interview, it came out that he had stopped engaging with treatment and was in two minds about trying again. Although tenuous, he may have used the interview as an unconscious medium to marshal his thoughts, as at the end of the interview/debriefing period he said he would re-engage with the NHS. On a positive note I intend, with Martin’s consent, to put into the public domain his story via a case study and having it published within an academic journal. Martin’s participation and my allowing him to do so has been an important learning exercise for me and one, that in the future, will make be a better, more experienced researcher.
Initially this project was based within the School of Art and Media, was quantitative and set out, via questionnaires, to gather information from men with EDs, people within the media, health care workers and the general public about their opinions of EDs in men and how in turn any issues could be better marketed. Over time the scale of the study caused some personal turmoil as I began to doubt that such a study, undertaken by one person with no funding, would gather enough information within the PhD time frame or answer some of the personal motivations behind my desire to research. However, I did not feel confident enough to question my then supervisors and trusted that they knew best. In hindsight, to have a valid and reliable study, the workload would have been a logistical nightmare and probably impossible given the problems with red tape and restrictions the UK charity Beat placed upon their help in advertising. Beat took approximately six months to consent to advertise, and they had to be given an assurance that self-help groups affiliated to Beat would not be contacted for participants. Self-help groups were going to be approached for help in recruitment before Beat’s involvement.

After over two years of study, and without warning, my supervisory team was changed and I found myself in the School of Nursing, Midwifery and Social Work, with a single supervisor who felt that the study should be qualitative rather than quantitative, the focus being on gathering information solely from men with ED experiences which is the research submitted. Even now, looking at the information collected and presented in this document is daunting, as I am aware during the interviews I missed opportunities to pursue certain areas of the men’s stories. Looking back, it is fortunate that the change of direction took place. However, it was not without some trepidation as this involved having more contact with men with EDs. Given my personal history hearing stories relating to the worst period of my life was always going to be difficult, and it was! Whilst it caused many reflective and difficult thoughts and emotions, it did not, as I originally worried, cause any relapse of my own ED.
13.10 – Rounding up

Having experienced a mental illness, where a common trait is perfectionism and self-loathing/self-critique, this has been an extremely difficult section to write; trying to sort legitimate academic considerations from the myriad of things I believe I could have done better, even if in reality that was not the case. To some, a number of the problems may seem trivial; changing supervisors is quite common (I am led to believe). A new supervisor brings new ideas. For myself the new ideas meant that I had to give more of myself than I felt I could, and this caused a lot of inner conflict. Thankfully the new ideas made this a much better piece of work. Moreover, my lasting disappointment is not having used Chris’s full interview and analysis. Whilst it may seem an occupational hazard of a novice researcher, it still does not lessen the disappointment of not sharing Chris’s story and for Chris, the opening up of his inner thoughts, for someone to discard them.
CHAPTER 14 - CONCLUSIONS

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or atypical anorexia/EDNOS

Gareth Lyons
The study was designed with the aim (Section 3.1) of exploring and documenting the lived experiences of men who have experienced anorexia nervosa or a-typical anorexia/EDNOS. From this three objectives were identified:

1. To explore the lived experiences of males with anorexia or an a-typical anorexia/EDNOS, focusing on how the illness affected their lives.
2. To add to the body of knowledge on male anorexia and a-typical anorexia/EDNOS by disseminating the findings of this study through publication in academic journals and conference presentations.
3. To clearly identify avenues for further research regarding male EDs.

**14.1 – OBJECTIVE 1 – EXPLORE THE LIVED EXPERIENCES OF MEN WITH EDs**

There can be no doubt in my mind that this objective has been achieved, the preceding chapters detail the stories and experiences of seven men who took part in the study. Each was interviewed using a method and location of his choosing and each story was analysed using the same techniques. Where possible, stories are presented using the participants’ words to add depth, authenticity and allow the reader to see how interpretations were made. This study went further than other similar research studies of men, such as Robinson et al. (2012) and Räisänen and Hunt (2014), as, unlike those studies, experiences of work under the influence of an ED were discussed, the men’s stories validating this topic of investigation and indicating this needs to be an area of future research.

The stories provided many avenues for further research and there were many paths which could have been followed. This was one of the reasons why Chapters 5 to 11 had some analysis embedded within them, rather than being presented as a chronological or biographical narrative as demonstrated in Browing’s (2017) ‘Ordinary Men’. Four themes were extrapolated from the interviews for further discussion within Chapter 12. These were; The Final John Doe (12.1), Masculinity - The Beast in Me (12.2), Not Working 9 to 5 (12.3) and Help! I Need Somebody – Bedlam Revisited (12.4).
14.1.1.1 - The Final John Doe

The men’s stories and background demographic data presented many similarities to the John Doe male anorexic identified within Section 2.6.2 of this thesis. These included,

- Approximate ages at reported onset.
- Being overweight pre-onset (five of the seven men).
- A family background which included experiences of close family members with weight and/or mental health problems.
- Six of the men reported isolation pre ED, including both platonic and sexual, the latter being more evident in the heterosexual men. The only man who did not experienced isolation experienced anorexia in his late twenties and his manifestation was different to the other men.
- A high proportion of men who participated identified as gay or bisexual (three of the seven men, 43%) than in other studies, Fassino et al.’s (2001) 20% and Räisänen and Hunt’s (2014) 30%. Whilst not statistically significant, it does potentially indicate higher risk for gay/bisexual men. However, it could also indicate that stereotypes associated with ED’s in men make it ‘easier’ for gay/bisexual men to come forward, seek help and be more active in social media/recovery groups.

14.1.1.2 - Masculinity - The Beast in Me

The men’s relationship with masculinity was complicated and perhaps, although speculative, is no different from many other men. In the main, men in this study verbally rejected traditional masculinity, Richard stated; “it means nothing nowadays, it’s all changed” (Appendix 11 - Richard Line 601) and Stephen wrote “I feel it is very old school and is now slowly opening to more variation rather than it being typical stereotypes like a man must like football etc” (Stephen Lines 221-223). Yet as a group their behaviours indicated many of the traits associated with it. For example, three (Henry, Michael and Richard) of the five men diagnosed over the age of 18 claimed they had no inclination that their behaviours were that of an ED, they only interacted with services as a last resort, perhaps indicating a level of stoicism and/or denial of the illness. There were high levels of educational/work-based success across the participants’ narratives, illustrating their desire
to achieve and compete. In a perverse way, masculine competitive traits (Kearney-Cooke & Steichen-Asch, (1990) and Barker (2007)) can be seen in the way the men fought their own bodies when engaging in their ED behaviours. In addition, some of the men did compare their perceived lack of masculinity through their inability to enjoy or play contact team sports which illustrated Swain’s (2000) conclusions.

With the exception of Russell, all of the men appeared to be isolated, in both a sexual and platonic sense, before the onset of their ED. The effects of the ED further emasculated the straight and bisexual men. Yet, for the two gay men, their weight loss brought a period of sexual popularity within the gay community, as their thinness made them more sexually appealing; “it was part of the addictive feature too, it was the skinnier I got the more I could flaunt myself, the more sexually promiscuous I became” (Alan Lines 679-81). This illustrates Connell and Messerschmidt’s (2005) refinement of the former’s original work, showing the different levels of masculinity, how on a global level their sexuality and ill health bars them from hegemony; however, on a local level they fulfil hegemonic criteria.

14.1.1.3 - Not Working 9 to 5

The third theme taken from the interviews was the affect EDs had on the men’s working lives. The employment of all of the men interviewed had been affected, in some cases this had been worrying about the ramifications of disclosure. The men who did disclose had varied experiences, with Kevin working within the largest organisation (civil service) having perhaps the worst experience of an employer and possibly grounds for constructive dismissal. Two of the seven men (Michael and Russell) changed their careers because of the effects of their ED; Kevin took a year’s unpaid leave in order to try and get better; Henry who at the time of the interview was twenty-seven had never worked full time because of his health, taking a succession of temporary jobs.

Given the experiences presented in the narratives, questions raised in Section 1.4.4 ‘Stigma and the Capability to Work’ in relation to competence and capacity were appropriate. Six of the seven men reported a drop in their ability to perform their job role due to physical and mental degradation The one man who did not report such problems was Michael but he did change his career to something less stressful. Richard described how he believed that if he had told his employer he had cancer he would have got more understanding and better treatment, sums up the conclusion from this theme. What the men’s experiences
demonstrated was a need for further research in this area focusing on attitudes and experiences within employment.

14.1.1.4 - Help! I Need Somebody - Bedlam Revisited

The men’s treatment experiences differed greatly with the much maligned ‘post code lottery’ in evidence. John for example, who was living in an area with specialised ED services, found himself seeing a ED specialist inside of three months. Stephen (a minor at the time) had to wait ten months, and Alan had to wait two years, even though he lived 20 miles from a specialist service. Richard’s treatment experience at best can only be described as shocking. After collapsing and being treated for physical ailments in hospital he found he could not get NHS treatment as he was not deemed serious enough after discharge (presumably because his BMI had increased whilst in hospital). Russell felt that he had such a bad first experience with his local mental health team, he refused to engage with them and spent a considerable amount of money getting private health care. He said of his experience “For all I know I could have the world’s greatest NHS mental health team literally down the road and I just don’t want anything to do with them” (Russell Lines 871-72).

In keeping with previous research (Burton and Warren, 2001; Colton and Pistrang, 2004) it was apparent in the men’s narratives that they felt, that a ‘one cap fits all’ approach did not work and, although based on scientific evidence, the emphasis on weight restoration over psychological well-being was brought into question. This was especially so for the two men who had experienced in-patient treatment, who felt that they still had not been offered support in facing the underlying issues of their ED, “nothing really was done to tackle what it was that was going wrong” (Michael Lines 296-98). Furthermore, there were a number of instances where the men were treated in a discriminatory fashion because of their gender, leading to them questioning themselves. One of the men justified the discrimination, commenting on “2000 years of patriarchy” (Kevin Line 452). While Kevin’s comment may have been tongue in cheek it illustrated his perception of being a second-class citizen, a finding in keeping with Paglia & Peterson (2017), who identified victim/oppressor narratives around perceived patriarchy as barriers to men. The men experienced communications which referred to them as females, a unit with no male toilets, worksheets and questions tailored to females, and in one case a group where the

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relationship. However, they also noted single men generally experience avoidable ill health episodes and shorten life expectancy.

All of the men came to the study via adverts placed by Beat. A number of them were active within ED fund-raising/activism/charity work and it was therefore surprising the nature of the comments aimed at the ED charities within the men’s narratives. Richard commented “Beat, I feel is a money whore as a charity” (Appendix 11 - Richard Line 761-63) being the most disparaging. Whilst the men felt that Beat did some good research, they were dissatisfied with how corporate the charity appeared, its lack of a male ED presence, its female orientation in website design (please note comments were made before Beat’s website redesign) and its fund-raising activities, the latter seeming more important than helping the individual. Around half of the sample had experienced MENGET and felt more kinship with the charity due to its male focus, however a number of the men had not heard of it. All of the men based in the north of the country commented that they felt the charities were too ‘Southern England’ focused. Worryingly, none of the men engaged with the charities prior to their diagnosis, indicating attempts to raise awareness of male EDs had not been successful.

**14.2 – OBJECTIVE 2 - TO ADD TO THE BODY OF KNOWLEDGE**

This objective will be met with the publication of this thesis. As highlighted in the previous section, this thesis adds further dynamics, particularly in relation to employment, services for EDs and experiences of charitable organisations from the perspective of men who have experienced EDs, extending the existing body of knowledge and bringing new understandings to the plight of men with EDs. In addition to the publication of my thesis, the findings will be published in academic journals and presented at national and international conferences.

Although not an academic journal there was an article published in the Conversation (Lyons 2015) which was based around some of the information within the introductory chapter of this thesis. It was interesting in that one of the comments on the article referred to me as being female despite my first name (Gareth) and my photograph being displayed, potentially illustrating gender stereotyping even within an academic community. I also
made use of the opportunity to present a synopsis of my work at an internal event at the University of Salford.

14.2.1 - POTENTIAL ARTICLES FROM THIS WORK

There are a number of potential articles in this thesis which I feel would add to the body of knowledge re men and EDs both within the academic and clinical communities. These will be;

- An edited version of all of the research and conclusions contained within this thesis.
- Four separate in-depth reports into the individual themes presented in this work.
- In conjunction with the men who took part in this study each of their stories could be co-constructed and released as a case study. This would include Martin whose story was not included within this work.
- There is also an opportunity, probably best if written by a third party, to provide a narrative reflective account of the research journey as undertaken by a person who had direct experiences of EDs.

14.3 – OBJECTIVE 3 – IDENTIFY AVENUES FOR RESEARCH

This study has provided many more questions than answers, which being its exploratory nature is no surprise and gratifying, as it shows the authenticity of the original idea to research. Avenues for future research are as numerous as branches which stem from a tree; some will be more appealing than others because they fit within the existing interests of researchers in the field. However, I would urge researchers to consider less well researched area, such as employment and EDs, as these experiences also impact on mental wellbeing. There is no doubt that further research is needed. Whilst the shared experiences within the seven men’s stories are compelling, it cannot be said that they speak for all men with EDs. Therefore, a primary avenue for academic research would be to provide more qualitative research exploring men’s experiences of EDs. Within the themes identified in this thesis the following questions were raised within this work which need investigating.
14.3.1 - RESEARCHING FUTURE JOHN DOES

The stories showed, in conjunction with existing literature, many shared traits/characteristics and signposts for people with EDs. It is clear that through research a greater understanding into the types of people who are susceptible to EDs will potentially help to identify people before an ED takes hold. Unsurprisingly the longer the experience of an ED without treatment the worse the prognosis (Räisänen & Hunt, 2014).

14.3.2 - FUTURE MASCULINITY RESEARCH

A number of gender issues were experienced and highlighted by the men demonstrating a need to examine the potential of emasculation and the effects this may have on men. Within Section 13.3, the idea of a missed theme was considered which revolved around their experiences of gender (being male with anorexia). The men’s stories individually perhaps can be seen as insignificant one offs, taken as whole they are more powerful especially when added to the experiences presented in Robinson et al. (2012). Kevin’s throw away comment suggesting that the discrimination he experienced was “a good corrective for 2000 years of patriarchy, so I can’t complain that much” (Kevin Lines 452-53), as an acceptable reason for the gender inequality highlights the need to investigate how to build men’s self-esteem, perhaps focusing on positive psychology. It may also not have helped that Kevin actively studied feminist theory and history whilst at university, perhaps accounting for his acceptance of his collective guilt.

Although possibly controversial, the stories the men provided together with the available literature, leads me to the conclusion that research not only needs to investigate masculinity and our views of it, but the views of those in powerful positions such as policy makers, academics, charity budget holders, towards men in general. Urban myths stereotype anorexia as an illness of white middle class teenage girls (National Institute of Mental Health, 2014) and it is therefore not beyond the realms of possibility that men with anorexia are stereotyped as being white and ‘privileged’, which in our world of identity politics would place such men at the bottom of any hierarchy. Without doubt research needs to further examine the differences in attitudes and treatment towards men and women with EDs.
No men took part in this study who had not interacted with health services. As such traditional masculine barriers to treatment (Charmaz, 1995; Courtney, 2000; Duker and Slade, 2003; Treasure, 2005; Peat et al., 2008) need to be circumvented and research has to somehow find men who have not sought help. This is an extremely difficult task as this study showed that self-awareness of EDs in men was low and the first awareness was often their first contact with health services. Perhaps a way of achieving this, is to maybe try to recruit family members. Stephen, Michael and Henry all reported family members were aware of problems before they were, and this was also my own personal experience.

14.3.3 - FUTURE RESEARCH INTO EMPLOYMENT AND EDS

This study has clearly showed that there are questions which need to be asked and answered in relation to the effects of EDs in the workplace. Beat, in conjunction with the Employers Network for Equality & Inclusion (2016), identified this in a publication aimed towards employers helping people with EDs or spotting signs. However, whilst mental health discrimination is covered by employment laws, we need to not forget how EDs affect day to day capability and capacity to work, which the men mentioned, and the problems of isolation at work and feelings of worthlessness that an individual may face. This would be an ideal avenue for a future research project, allowing multi-professional collaborations.

There was reticence within the men to share knowledge of their ED, especially before being appointed, and this appeared evident regardless of the job. This suggests there might be a need to further examine the knowledge and attitudes of employers, especially as the men in general did not appear to lose their jobs when disclosing the ED pre/post job interview. However, an employer would be unlikely to reject a person for a role and cite anorexia as a reason due to this being discriminatory.

14.3.4 - RESEARCH QUESTIONS FOR HEALTH CARE & CHARITIES

Whilst I expected some comments in the men’s stories in relation gender stereotyping outside of health care treatment, I did not expect the reporting of gender issues at the levels reported by the men. Although a number of stories regarding treatment of EDs came from one-man, other participants recalled similar negative experiences. Section 14.3.2
highlighted issues in relation to a wider societal view of masculinity or men. There is a clear need for further research into the levels of discrimination (buildings/paperwork/staff) within male ED provision, and perhaps health provision per se. As a man I cannot help but wonder at how the incidents detailed in Section 12.4.5 would have been viewed if they involved a female rather than a male.

In the men’s stories it was clear that they felt a one cap all fits all approach was not the most effective way to treat their ED. This belief was mainly aimed at treatment which assumed homogeneity among those with EDs. Future research needs to examine the strategies for treating males with EDs by building on existing studies, such as this, which considers treatment from the service users’ perspective. For example, Henry, Michael and Richard all experienced treatment issues when the focus was on a target BMI. There is also a need to examine the collaboration between the patient and practitioner within treatment, with perhaps certain personality types responding better to different interventions as illustrated by Russell’s choice of therapist/dieticians.

Whilst the men did not encounter any problems with their GPs as the first point of contact in terms of being taken seriously, what was worrying was the different level of services available within trusts in different regions. The “post code” lottery has been highlighted for many illness, and it evident in the stories that the men had very different treatment experiences and paths into actual ED treatment. Some of the men experienced psychology/counselling whilst waiting for specialist ED service, and perhaps in the current socio-economic climate, it begs the question of exploring the effectiveness of non specialist counselling whilst waiting for an ED specialist appointment.

Perhaps the most important recommendation outside of the need for more research is that there is a need to create awareness in society that men can become ill from EDs. Awareness has to be across genders and not just focused on men as, the stories presented in this work show, the importance of loved ones in preventing EDs from escalating can be pivotal to the recovery process. This is something that both the health services and ED charities need to focus on in the first instance. Unfortunately, this recommendation is very similar to that of Cooperman’s (2000); “EDA need greater publicity about men with eating disorders and to highlight this issue.” (p 19). Five of the seven men in this study had no idea that they were suffering from an ED despite the symptoms they were experiencing.
One of the men (Kevin) who did identify his ED before seeking help, only began to look for ED charities after seeing his GP for the first time, clearly highlighting the need for research to be undertaken to establish the best ways to effectively raise awareness.

Whilst all the men praised parts of what Beat and MENGET did, they were also as a group critical. The men recognised that many more females present with EDs than males and the men who had been in contact with females with EDs whilst in treatment showed much empathy. However, they still felt marginalised by Beat in terms of literature and their voices being heard and in this respect the charity would be wise to research ways in which to better engage men. The study of Cooperman (2000) has been cited on a number of occasions and it appears from the literature review and narratives that that Cooperman’s recommendations have not had great effect. Cooperman (2000) was funded by the National Eating Disorders Association now called Beat and it is vital that they fund a follow up piece of work, which will give an insight into how the lives of men with EDs have changed in the last 20 years.

MENGET simply needs to build its profile and champion academic research into male EDs. Not one of the males who responded to this study came via MENGET and there was no evidence that the charity promoted the study, save an email saying they would. Richard who had direct experience of charities, was very critical of MENGET and his comments in relation to Beat and MENGET not working well together could perhaps be the focus of research examining the collaboration and effectiveness of the various charities, which in one way are working for the same goals but are competing against each other for support and funding. There is also a need to establish how many charities there are in the UK in relation to EDs and geographically plot them on a map so that people can seek help closer to home if desired. Beat and MENGET were the focus of this research because at the start of the project they were two most high-profile charities, which they still are. During the interviews only one other ED charity was named.

14.4 – GROWING UP DURING A PHD, A FINAL REFLECTION

This work has taken a long time to produce, and in order to understand many of the ideas and theories encountered during this process, I have had to open my mind and critically
think about topics which I would never have thought existed, especially within the methodological chapter. This has allowed me to marshal my thoughts, realise what I believe in and experience a freedom of thought and ability to share my views I did not feel I had previously.

Michael said he felt that “the general view of eating disorders being about young wealthy girls wanting the attention is hugely, I’m not sure if damaging is the word, but really dangerous, but not just for men but also for older women” (Michael Lines 1091-95). He said “I’ve been there [hospital] with women who are over 70. I’ve also heard of men being over 70” (Michael Lines 1105-06) ... “it can hit absolutely anyone and it will rip apart your life regardless of how much money you’ve got.” (Michael Lines 1115-17)

I believe an oppressed verses oppressor mentality, which stems from critical theory/post modernism eventually leads to a continuation of any problems, with merely the oppressed becoming the oppressor and the oppressor the oppressed. I believe creating divisions does not create equality; this is only done through equality of opportunity and respect. On reflection I feel that the critical thinking on my PhD journey has allowed me to come to this conclusion, people may agree or disagree, that is freedom of choice. I feel that my PhD has allowed me to be more balanced in my thinking, more thoughtful and less reactionary and as such better able to make a contribution within society and the research community.

On my own I know I cannot change the world, and this journey has enabled me to laugh at my initial hubris that I was going to change the world, without understanding how the world works, how academia/research works and without evidence. I still do not want people to have similar experiences to myself and I am still angry. I am however better able to rationalise my feelings and better able to work towards potentially helping people through knowledge.

14.5 – FINAL CONCLUSION

This thesis has in its own way given a voice to seven men from a community, who had been largely ignored by society and academia. In this respect this work, whatever one’s opinions of its strengths and weaknesses, adds to the existing, but small body of knowledge. In terms of original contribution, there is no other work to my knowledge,
which has asked men about the impact of EDs on their everyday lives, and in particular within the workplace, this research being the first to offer such insights.

When I started this process, there was very little work specifically on EDs in men. This was exemplified when writing the initial research proposals and study background. As the study progressed I thought there would be more male specific research which could have been used within this work, but unfortunately this was not the case (Section 2.3.1 figure 4)

It cannot and should not be denied nor ignored that there are many illnesses which require research, and statistics (N.H.S Digital 2013) indicate that the numbers of men within inpatient treatment is low, which presumably hampers funding. These figures, though, do not indicate the numbers of men in non-inpatient treatment nor those who are not able/willing to seek help. Studies have indicated a rise in EDs in men (Braun et al., 1999; Brown, 2007; Knowles, 2011; Räisänen and Hunt 2014; Skolnick, 2014), but there seems to have been very little impact upon the number of studies produced within academia and one must question why.

Many of the conclusions/recommendations within sections of this chapter (14.3.1, 14.3.2, 14.3.3, 14.3.4) all stem from the need for more research and understanding. Without further research we will be no further forward than the point we are at now. This work succeeded in its aim of exploring the lived experiences of men with anorexia, a-typical anorexia/EDNOS. But it is just that, an exploration an overview, a ‘geological’ report which shows an academic gold mine of information to be extracted, processed and presented for the greater good, rather than accepting the status quo and men in the UK continuing to have experiences as described by Michael;

I would not wish this on my worst enemy and that again goes back to why I am doing this interview because hopefully what you are doing will help someone not go through this because it’s really not nice at all (Michael lines 1311-15)
An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

CHAPTER 15 - APPENDICES

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### 15.1 – APPENDIX 1 – STUDIES USED IN THE LITERATURE REVIEW

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Appendices
An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

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An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

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<td>Males Assessed by a Specialized Adult Eating Disorders Service: Patterns Over Time and Comparisons with Females Button, E; Aldridge, S; Palmer, R</td>
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<td>Severe Eating Disorder Initially Diagnosed in a 72-Year-Old Man Manejias Parke, S G; Yager, J; Apfeldorf, W</td>
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<td>Epidemiology of Anorexia Nervosa in Men: A Nationwide Study of Finnish Twins Raevuori, A; Hoek, H W; Susser, E; Kaprio, J; Rissanen, A; Keski-Rahkonen, A</td>
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<td>2009</td>
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<td>Gender difference in the prevalence of eating disorder symptoms Striegel-Moore, Ruth H; Rosselli, Francine; Perrin, Nancy; DeBar, Lynn; Wilson, G Terence; May, Alexis; Kraemer, Helena C</td>
<td>X</td>
<td>2009</td>
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<td>Nutritional knowledge, eating attitudes and chronic dietary restraint among men with eating disorders Scaglioni, F B; Nakagawa, K A; Campos, R M; Kotait, M; Fabbri, A; Sato, P; Cordas, T A; Appetite</td>
<td>X</td>
<td>2009</td>
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<td>Contribution of Emotion Regulation Difficulties to Disordered Eating and Body Dissatisfaction in College Men Lavender, J M Anderson, D A</td>
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<td>The Measure of a Man: Associations between Digit Ratio and Disordered Eating in Males Smith, A R; Hawkeswood, S E; Joiner, T E</td>
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<td>Young man with anorexia nervosa Cazzuffi, A; Manzato, E; Gualandi, M; Fabbian, F; Scanelli, G; Journal of the Royal Society of Medicine Short Reports</td>
<td>X</td>
<td>2010</td>
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<tr>
<td>Female medical students are estimated to have a higher risk for developing eating disorders than male medical students Dissing, A S; Bak, N H; Toftegaard Pedersen, L E; Petersson, B H; Danish Medical Bulletin</td>
<td>X</td>
<td>2011</td>
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<tr>
<td>A Clinical Comparison of Men and Women on the Eating Disorder Inventory-3 (EDI-3) and the Eating Disorder Assessment for Men (EDAM) Stanford, S C; Lemberg, R; Eating Disorders -The Journal of Treatment and Prevention</td>
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<td>Study Name, Authors, Publisher</td>
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<td>A comparison of eating, exercise, shape, and weight related symptomatology in males with muscle dysmorphia and anorexia nervosa</td>
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<td>Murray, S B; Riegerb, E; Hildebrandtc, T; Karlova, L; Russell, J; Boone, E; Dawson, R T; Touyza, S W; Body Image</td>
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<td>Adolescent Male with Anorexia Nervosa: A Case Report from Iraq</td>
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<td>Younis, M S; Ali, L D; Child and Adolescent Psychiatry and Mental Health</td>
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<td>Being men with eating disorders: Perspectives of male eating disorder service-users</td>
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<td>Robinson, K J; Mountford, V A; Sperlinger, D J Journal of Health Psychology</td>
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<td>Comorbidity of Partial and Subthreshold PTSD among Men and Women with Eating Disorders in the National Comorbidity Survey-Replication Study</td>
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<td>Mitchell, K S; Mazzeo, S E; Schlesinger, M R; Brewerton, T D; Smith, B N; International Journal of Eating Disorders</td>
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<td>Do Men with Eating Disorders Differ from Women in Clinics, Psychopathology and Personality?</td>
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<td>Nuñez-Navarro, A; Agüera, Z; Krug, I; Jiménez-Murcia, S; Sánchez, I; Araguz, N; Gorwood, P; Granero, R; Penelo, E; Karwautz, A; Moragas, L; Saldaña, S; Treasure, J; Menchón, J M; Fernández-Aranda, F; European Eating Disorders Review</td>
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<td>Does Depressed Mood Moderate the Influence of Drive for Thinness and Muscularity on Eating Disorder Symptoms among College Men?</td>
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<td>Grossbard, J R; Atkins, D C; Geisner, I M; Larimer, M E; Psychology of Men and Masculinity</td>
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<td>Eating Disorders and Pathological Gambling in Males: Can They Be Differentiated by Means of Weight History and Temperament and Character Traits?</td>
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<td>Claes, L; Jiménez-Murcia, S; Agüera, Z; Sánchez, I; Santamaría, J; Granero, R; Fernández-Aranda, F Eating Disorders</td>
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<td>Claes, L; Jiménez-Murcia, S; Agüera, Z; Castro, R; Sánchez I; Menchón, J, M; Fernández-Aranda, F European Eating Disorders Review</td>
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<td>Mycobacterium chimaera Causes Tuberculosis-like Infection in a Male Patient with Anorexia Nervosa</td>
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<td>Alhanna, J; Purucker, M; Steppert, C; Grigull-Dabor, A; Schiffer, G; Gruber, H; Borgmann, S International Journal of Eating Disorders</td>
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An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons
Appendices
An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS
An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

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Appendices
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<td>Does Being Overweight or Male Increase a Patient’s Risk of Not Being Referred for an Eating Disorder Consult?</td>
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<td>Mangweth-Matzek, B; Kummer, K K; Pope, H G; International Journal of Eating Disorders</td>
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**15.2 – APPENDIX 2 – BEAT RESEARCH CRITERIA**

**Procedure for working with Beat** (Taken from Beat’s website (https://www.b-eat.co.uk/research/work-with-us-as-a-researcher))

We ask for the following requirements to be able to advertise a research request on your behalf. All information can be sent via email to research@b-eat.co.uk:

- Your research proposal including any protocols, consent forms, questionnaires or any other materials participants will be exposed to.
- Confirmation that full acknowledgement will be given to Beat in any reports that result from the research.
- Details of where and in what form you intend to publish your findings.
- Send me an attachment with the title of your project (of no more than 70 characters in length including spaces); a synopsis (of no more than 255 characters in length including spaces), a University logo or image (in high resolution .jpeg or .png format), name of author, their affiliation and email address. This attachment should also include the text for the main body of the page arranged using the following subheadings:
  - What is the purpose of the research?
  - Who can take part?
  - What does the study involve?
  - How can you take part?
- Confirmation that you have read and agree to abide by the guidance on confidentiality and safeguarding set out in the following publications by the British Psychological Society – ‘Code of Ethics and Conduct’ and ‘Code of Human Research Ethics’.
- Please include information about our Helplines in your de-brief.
- An email confirming ethical approval sent from the relevant Research Ethics Committee sent to research@b-eat.co.uk, or a hardcopy of signed ethical approval posted to the Research Officer at Beat’s address (Beat, Wensum House, 103 Prince of Wales Road, Norwich, NR1 1DW).
• An estimated date by which you will aim to or must finish recruiting participants.
15.3 – APPENDIX 3 - RESEARCH STUDIES ADVERTISED BY BEAT


1. A pilot study testing a Guided self-help intervention for eating disorders
2. An exploration of how therapist gender and body confidence impact upon the patient
3. Anorexia nervosa, the brain, and reward
4. Assessing a new clinical resource for anorexia nervosa: Stories of recovery from anorexia
5. Body image in Anorexia and Bulimia
6. Body Image Perceptions within Eating Disorders
7. Brain ‘reward mechanisms’ in sisters of those with current (or history of) Anorexia Nervosa
8. Brain Reward processing in people with Bulimia
9. BRITE: Brain directed interventions for eating disorders
10. Disordered Eating Attitudes and Behaviours: the impact of Emotional Intelligence, Health Literacy and Self-Esteem
11. Eating, food and imagery
12. Emotions in women with eating disorders
13. Exploring the therapeutic relationship between you and your therapist – Phase 2
14. Family and caregivers: unmet needs, involvement in treatment, coping strategies, carer burden and psychological health
15. Feelings and Faces
16. Invitation to take part in a focus group at Durham Uni on the association of ‘personality types’ and eating disorders
17. Involuntary detention under the Mental Health Act for Anorexia Nervosa
18. NICE guideline consultation
19. Personality and Anorexia Nervosa
20. Personality, thinking and emotional style in people with Anorexia Nervosa
21. Post-traumatic Stress Disorder (PTSD) after inpatient admission for eating disorders (ED)
22. Pride in Body Image and Eating Attitudes (in females with or without a diagnosis of an Eating Disorder)
23. Psychological Inflexibility and distress in Body Dysmorphic Disorder
24. Sibling Support Survey
25. Social processing in young adults and people with eating disorders
26. The development and validation of a shortened version of the Eating Disorder Examination Questionnaire (EDE-Q)
27. The experience of an eating-disorder as an immigrant to the United Kingdom
28. The experience of being a mother with Anorexia Nervosa
29. The experience of loss of control during a binge eating episode for those people with Bulimia Nervosa or Binge Eating Disorder
30. The experience of pregnancy
31. The father-daughter relationship and Anorexia Nervosa
32. The feasibility and acceptability of a Self-help manual of Cognitive Remediation Therapy for Anorexia Nervosa
33. The individual experience of seeking help for bulimia nervosa
34. The prevalence of eating disordered and depressive symptoms in endurance athletes and the general population
35. Transcranial direct current stimulation (tDCS) in bulimia nervosa
36. Triggers and onset in Anorexia Nervosa: a qualitative research project
37. What are the impacts of long term bulimia on post-recovery self-concept
38. What does it mean to have distorted body image in eating disorders?
39. Women’s experiences of cognitive-behaviour therapy for the treatment of bulimia nervosa
40. Your experiences of receiving therapy for your eating disorder
Men Needed to Speak About Their Eating Disorder Experiences

The University of Salford needs men who have experienced an eating disorder to take part in a study investigating their lived experiences of their illness.

Since the millennium, it has been reported that the prevalence of eating disorders in males has increase by 66%. Figures use to state that around 10% of sufferers were male, but it is now reported to be closer to 25%.

Researchers have examined the effects of eating disorders from a clinical perspective, but very little research has been done where men have been asked about their own experiences of everyday living with an eating disorder, which is why this study has been created.

What you have to do?

To take part in this study you will need to complete a short questionnaire and take part in either an on-line text based interview using a messaging service such as Skype or a phone interview. Participants will be asked to share their experiences of life with an eating disorder, focusing on areas such as

- how people treat(ed) you at work, socially, at home etc.
- how you felt about seeking help or why you haven’t sought help.
- how you feel about yourself and how you feel the illness has affected you?

Who can take part?

We are looking for males over the age of 18 who have had or currently have an eating disorder in the form of Anorexia Nervosa or an Eating Disorder Not Otherwise Specified.
We are also looking for men who have not sought the help of the health services as well as those who have.

**Location**

The questionnaire and interview are web/phone based so can take place wherever you feel comfortable.

**Potential side effects**

Talking about personal experiences can sometimes be distressing, at the end of the interview there will be time (off record) to discuss your feelings and you will be given a list of potential contacts if you feel you wish to speak to someone else. Furthermore, you can withdraw from the interview and any information you have shared will not be used in the study.

For more information contact

Gareth Lyons at: g.i.lyons1@edu.salford.ac.uk.

Version 1 (30th Jan 14)
Invitation to participate in research study

My name is Gareth Lyons and I am doctoral student at the University of Salford undertaking a research project examining the experiences of men who have had or who currently have an eating disorder in the form of Anorexia or an Eating Disorder Not Otherwise Specified (EDNOS), specifically investigating their feelings and experiences of living with illness. If you would like to consider participating in the study you will be asked to complete a short background questionnaire and then take part in an interview using a text based messaging service such as Skype. If you decide to take part in the research all the information you give will be anonymised.

Enclosed with this letter is an information leaflet that gives you more details about the study and what you will be asked to do if you decide to take part. Please read the leaflet and if you feel that you would like to participate in the research, please contact me on the phone number or e-mail addresses at the top of this letter. Once you make contact please ask as many questions as you want and I will attempt to answer them before you decide to participate.

If you decide to participate the information you give be kept confidential, your name will be anonymised and any information which could reveal your identity will be changed or excluded.
If you are interested, please contact me via phone or e-mail, **Your help would be greatly appreciated**

Yours sincerely,

Gareth Lyons
**Title:** An exploration of the lived experiences of men who have an Eating Disorder

**INVITING YOU TO HELP**

- I am trying to find out about the life experiences of men who have/had Anorexia Nervosa or an Eating Disorder Not Otherwise Specified. If you feel you are able to share your experiences to help expand the knowledge of eating disorders in men then I would like to invite you to participate in the study. Before deciding if you would like to help or not, please take time to read the rest of this leaflet and if you wish, discuss taking part with others.

**WHAT IS THIS STUDY ABOUT?**

- There is very little research examining the day to day lives of men with eating disorders, research tends to focus on topics such as weight, body image etc.

This study is different as it aims to explore the experiences of men with eating disorders and how they impact on different aspects in everyday life. Areas for discussion might include:

- Relationships - with friends, family and work colleagues etc.
- Day to day living, do men feel their eating disorder has affected their work/study or hobbies.
- Personally, how as a human being they feel about having an eating disorder and how they feel it affects them.
- If you feel that you would like to talk about your experiences of your eating disorder then please read the rest of this leaflet.
WHAT IS THIS STUDY HOPING TO DO?

- By interviewing men, I hope to build up a bank of information about men’s experiences, feelings and their emotions around living with an eating disorder.

This information will be used by researchers and health professionals in the future to help raise the awareness of eating disorders in men within the health community and society as a whole.

DO YOU HAVE TO TAKE PART?

- No, you do not have to take part, and if you do take part you can withdraw at any time and any information you have given will not be used in the study.

BEFORE PARTICIPATING IN THE RESEARCH

- You will be given information as to what you will be expected to do if you decide to participate in the research. Once you have read the information (this leaflet) there will be opportunity for you to contact the researcher to ask questions about the research.

WHAT WILL HAPPEN DURING THE RESEARCH?

- Before participating you will be asked to sign a consent form. If you wish, the form will be explained to you so that you are clear about what you are agreeing to do.

Any information you provide will be confidential, you will be given a pseudonym, and any information which may identify you will be changed.

- The research is in two stages
  1. If you are happy to participate and you have signed the consent form, you will be asked to complete a short background questionnaire.
  2. After completing the questionnaire, the researcher can arrange a convenient time for an interview using a messaging service such as Skype or the telephone. We aim to have the whole process completed within the space of a few weeks.
• **The interview will last approximately one hour** and what is recorded will remain confidential between you and the researcher. However, the researcher is duty bound to report anything that you may say which is illegal.

• At the end of the interview there will be some time for you to talk about any aspects of the interview you found upsetting or difficult. This information will not be included in the research.

• You will be free to terminate the interview at any time. If you do decide to no longer participate in the research the information you have given will be destroyed and not used in the research.

• At the end of the interview you will be given an information sheet which will list organisations and bodies where you may find help (if needed).

**WHAT HAPPENS AFTER THE INTERVIEW**

Once the data is collected it will be analysed and anonymised by the researcher and stored on a secure computer system.

Once this work is complete the researcher will write a report bringing together all the information which has been found.

**CONFIDENTIALITY**

• As stated previously what you share will remain confidential between you and the researcher. The information that you provide will be anonymised used in the final report or in any subsequent publications and presentations.

• In exceptional circumstances confidentiality may be broken and appropriate agencies informed, the only circumstances which would justify this are,
  
  o Where there is a real and present threat to life of self, or of a child in their care
  
  o When not to do so would be breaking the law
WHAT ARE THE BENEFITS OF PARTICIPATING IN THE RESEARCH

- By taking part in this research you will expand the knowledge of what it is like for a man to live with an eating disorder in the 21st Century.

The information you provide will add to a growing body of knowledge about eating disorders in men, studies, giving a better understanding of eating disorders to those helping men in the future.

You may also find positive personal benefits from sharing your experiences.

WHAT ARE THE DRAWBACKS TO PARTICIPATING IN THE RESEARCH?

- It is possible that in talking about your experiences of your eating disorder you may experience some distress. At the end of the interview the researcher will provide an opportunity to talk about any aspects of the interview that you found distressing. This will not form part of the research. *However, if you feel that talking about your experiences will cause distress then you will need to ask yourself if it right for you to take part? In any form of research your health comes first.*

- If, after a period of debriefing you feel that you would like further help, the researcher will be able to direct you to appropriate services that you can choose to contact.

MAKING A COMPLAINT:

- If you wish to make a complaint at any time during the research then please contact,

  Dr S McAndrew  
  Room MS1.39  
  School of Nursing, Midwifery & Social Work  
  Mary Seacole Building  
  University of Salford  
  M6 6PU  
  s.mcandrew@salford.ac.uk
WHAT NEXT?

- Think about if you want to participate in this study, if you are unsure talk to someone you trust, if you need further information don’t hesitate to contact me using the details below.
- If you want to take part in the study contact me at email and I will send you a consent form

Researcher’s name: Gareth Lyons

E-mail g.i.lyons1@edu.salford.ac.uk

Thank you for taking time to read this leaflet.

Version 2 (17th May 14)
Title: An exploration of the lived experiences of men who have an Eating Disorder

Please tick the appropriate boxes

Taking Part

I have read the information sheet and I have been informed about the above research and I understand what I am being asked to do. ☐ ☐

I have been given the opportunity to ask questions about the project, and all questions have been satisfactorily answered. ☐ ☐

I agree to participate in this study which will include returning a completed questionnaire and being interviewed which will be transcribed and anonymised. ☐ ☐

I understand that my taking part is voluntary; I can withdraw from the study at any time and I do not have to give any reasons for why I no longer want to take part. ☐ ☐

If I do decide to withdraw I understand that the information I have given will not be used in the research. ☐ ☐

I understand that the information I give will only be used for this specific project. ☐ ☐

I understand that my personal details will be kept confidential. ☐ ☐
An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons

Appendices
The following short questionnaire is designed to gather preliminary data. All questions have been included because they will provide information that will benefit the study, but if you do not wish to answer any question please leave it blank.

Background

1. Age:

2. How would you describe your ethnicity?

3. How would you describe your sexuality?

4. What is your religion/faith?

5. What is your current highest Level of Education? (delete unsuitable options)
   GCSE       A Level       Graduate       Post Graduate

6. What is your occupation?

Eating Disorders

7. Have you sought medical help for your eating disorder? YES/NO (if yes please answer question 8, if no please answer question 9)

8. Answer these questions if you have answered yes to question 7
   a. What is the medical classification of your eating disorder?

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons
Appendices
b. What types of services you have accessed e.g. outpatient services, counselling,

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

c. Were the health services you accessed (delete unsuitable options)

Private  State  Both

d. What treatments, if any have you had?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Go to question 10.

9. Answer these questions if you answered No to question 7
   a. What type of eating disorder do you believe you are suffering from?

________________________________________________________________________

b. Briefly describe why you have not accessed medical help

________________________________________________________________________
________________________________________________________________________

10. Which of the following behaviours have you experienced during your eating disorder (delete unsuitable options)

Food Restriction  Y/N
Vomiting  Y/N
Laxative Use  Y/N
Excessive Exercise  Y/N
Other ____________________________________________________________
11. How long do you think you’ve had an eating disorder for?
__________________________________________

12. How did you find out about this study?
__________________________________________

Version 2 (19th March 15)
The contact information listed below is a useful guide to where you can get help and support with your eating disorder.

This is not an exclusive list and to find non-emergency eating disorders specific help in a certain geographical the best resources to use are the Beat help finder (http://helpfinder.b-eat.co.uk/), NHS 111 (Phone 111) or by contacting your local GP.

For emergencies go directly to your local A&E Department.

**Beat**

This is the national charity for all eating disorders in the U.K. and offers information, a helpline and links to support services.

Helpline – 0845 634 1414

Web – www.b-eat.co.uk

For listings of self-help groups, therapists and counsellors - http://helpfinder.b-eat.co.uk/

**Men Get Eating Disorders Too**

This is a national charity for men with eating disorders. MGEDT does not offer immediate support and in this case, you should contact the B-eat helpline 0845 634 1414, NHS 111 (Phone 111) or the Samaritans on 08457 90 90 90 in the U.K.

Web - http://mengetedstoo.co.uk/
An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a typical anorexia/EDNOS

Gareth Lyons

Appendices

For general enquires email - sam@mengetedstoo.co.uk

NHS 111

NHS 111 is a free phone number which has replaced NHS direct and offers support, advice and information.

Phone -111

NHS Accident and Emergency Services

Go to your local A&E Department where you will be able to speak to a councillor.

The Samaritans

The Samaritans is a service where you can access someone to speak to at any time.

Phone - 08457 90 90 90 (This is not a free service)

Web - http://www.samaritans.org/

Visit a branch - http://www.samaritans.org/branches

Email - jo@samaritans.org

Write - Freepost RSRB-KKBY-CYJK, Chris, PO Box 90 90, Stirling, FK8 2SA

Mind

Mind is the national mental health charity and offers helplines and

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An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS
## APPENDIX 10 – BEAT CONFIDENTIALITY POLICY

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<td>Board of Trustees</td>
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<tr>
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<td>Jan 04</td>
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<td>Individual Support</td>
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<tr>
<td>Contact</td>
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<tr>
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An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS
Beat CONFIDENTIALITY POLICY

The Principle of Confidentiality

Beat Workers (staff; volunteers including Trustees; temporary staff; secondees and students ) should treat in confidence information about individuals (including other workers) that they receive in the course of or as a result of their work for Beat. The confidentiality principle helps to create an environment in which enquirers can speak freely and workers can work in safety.

When Would Beat Break Confidentiality?

The principle of confidentiality is fundamental to the work of Beat and an obligation of Beat as an organisation. Accordingly, breaking confidentiality is a serious matter. Beat workers must be prepared to account for such action. *Enquirers should be made aware of our confidentiality policy and the circumstances in which we might need to share information given to us with a third party.*

The only circumstances in which a breach of confidentiality may be justified are:

1. Where there is a real and present treat to life of self, or of a child in their care
2. When not to do so would be breaking the law

If We Do Have to Break Confidentiality

- The person involved must be informed if a decision is made to break confidentiality
- The reasons why the decision has been taken must be explained
- The repercussions of breaking confidentiality will also be explained
- The Chief Executive will be informed if a decision is made to break confidentiality and a report made of the details of the incident, action taken and any repercussions following the decision
Practical Aspects of Confidentiality

All Beat workers are given a copy of this confidentiality policy as part of their induction, and are required to sign and agree to abide by it. Managers are responsible for ensuring it is understood and adhered to.

Workers should only discuss enquiries within Beat Care should be taken that such discussions cannot be overheard by anyone outside the service e.g. other users or office visitors. No written information about individual calls, letters or e-mails should be taken out of the Beat office.

Information about an enquirer, including the fact that they have made contact, should not be disclosed to a third party, even to a partner or family member, without the expressed consent of the enquirer. Care should be taken not to give identifiable information about an enquirer unless permission has been given.

Workers operating outside the Beat office should not discuss enquiries with people outside the organisation that could reveal information that may identify the enquirer.

Workers may sometimes disclose personal information in training sessions or supervision. Such information must remain confidential to those sessions.

The confidentiality policy is part of your contract of employment and any contravention will constitute a disciplinary matter.

Compliance with this policy is a requirement of your contract of employment with Beat.
An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or atypical anorexia/EDNOS
Interview with Richard

Gareth:
Hello is that Richard speaking?

Richard:
Yes this is Richard speaking

Gareth:
Hi this is Gareth Lyons speaking from the University of Salford thanks for getting back to us. It’s been a bit of a pain actually organising this interview

Richard:
Yes sorry about that just I work and things

Gareth:
That’s no problem. It’s me to be honest with you. I work and I can’t access my email my university email at work so it’s a bit of a pain. Basically the interview is really about I’m researching about the lived experiences of eating disorders

Richard:
Yes

Gareth:
Basically what I want is I want to find out your opinions of what’s happened to you, why you may think some things happened to you. Basically what your experience is and what you think about it really.

It’s just basically the study I’m doing is that I’m asking guys about their experiences and hopefully next year when I come to submit my PhD there’ll be bodies of like 10 interviews with men specifically men who have got or who had anorexia and basically we can maybe push research in different directions. There’s very little research done which actively asked for the opinions of men outside...

Richard:
Yes the lived the experience there’s nothing like that

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS
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Appendices
Gareth:

30 Yes basically that’s what the research is. I had an eating disorder in the past and that’s basically where I’m coming from. In terms of the interview it will last approximately an hour so hopefully I won’t take too much of your time tonight. I’ll ask questions if you want to answer that’s brilliant, if there’s a question you don’t want to answer or anything like that that’s entirely up to you. If you don’t want to answer something then just don’t answer it, it’s entirely up to you in terms of what we talk about. Before we start you obviously filled the consent form in, do you want me to go through that again or are you just happy to crack on?

Richard:

38 Yes I’m just happy to crack on

Gareth:

40 Before we start are there any questions?

Richard:

42 No I think it’s been self-explanatory up to this point

Gareth:

44 Me being self-explanatory that’s a new thing! Okay then I suppose the first thing is really if you could give me some background to your eating disorder you’re eating disorder experience

Richard:

48 Well basically my eating disorder manifested itself when I was at college. I was rather large. I was 22 and half stone and I wanted to lose weight at college and a friend recommended that I went onto these websites which there were basically online chat forums where you could speak to other people about your weight loss and etc. Little did I know at that time that they were thinspiration websites and full of internet trolls out they were encouraging really extreme diets. They asked me to cut carbohydrates completely out of my diet then proteins out of my diet and then they asked me to manage on sugary tea and the sugar from that tea which I did and as a result I lost an extreme amount of weight almost double the body weight. I was 6 and half stone at my worst and when I went to university and I collapsed on my bed during xxxx at university with anorexia. Throughout my time at university I was exercising every single morning before lectures;
60 6am in the morning until my lectures started. I wasn’t eating and then I’d come home and do the same again. Compulsive exercise as well as anorexia

62 Gareth:

xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx

64 Richard:

xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx

66 xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx

Gareth:

68 Is that 18 is it?

Richard:

70 I was 19 at the time when I went to college xxxx. I was 18 just coming 19

Gareth:

72 And you went to university xxxx?

Richard:

74 It was xxxx I went to university but it wasn’t until xxxxxxx xxx that I actually collapsed

Gareth:

76 xxxxxxx xxxx; in that time that 2 year time you lost all that weight?

Richard:

78 Yes

Gareth:

80 Okay so when you were dieting then can you remember what you were feeling?

Richard:

82 I was feeling quite euphoric and was seeing results quite quickly and I thought this is quite good. I thought that people in the online chat rooms were genuine friends at the time but then they started getting nasty. The more weight I lost it wasn’t good enough for them and they wanted more and they wanted double and they wanted it quicker and they were egging me on. I was so desperate to lose the weight that I did it and eventually

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons

Appendices
I had no control over what I was actually doing. I didn’t realise at the time the disorder had taken over control of me. I lost control of the whole dieting and everything and it became an eating disorder. When I look back on my life I’ve always been funny with food anyway. Also [inaudible] tenancies as teenager but I suppose... also with OCD with cleaning and perfection when I was at university and at school with exams and things, I guess the traits were always there. The manifestation of it came to ahead with the online chat rooms where I lost control of what I was doing. I started bullying people, the disorder had taken over control of me. [inaudible] didn’t have any control over what I was doing, but I did feel euphoric. There was a time at its worst I felt really frightened and I wanted to get help but I didn’t obviously know there was help out there. I thought especially being a guy I thought it was maybe just a phase I was going through or something.

Gareth:

When you talk about websites inspiration websites I take it the people who were giving you advice and putting you under pressure (if I can put words in your mouth) are they dieting and so on?

Richard:

They were all for the male physique where it looked skeletal. The pictures I was seeing were pictures of young boys and young adolescent males with their hip-bone sticking out, their rib bones, and saying ‘eating is cheating’ and the words around it were eat then it would change the E to F so it was fat and it kept repeating. Just images like that and the people that were on it were obviously being these things themselves were ill and they played on new people that came to it and the images they were sharing were shocking and I still to this day don’t understand why these things aren’t policed because it’s dangerous. They promote the physique of a male looking skeletal and there is a lot of stigma out there at this minute that all guys want to look quite muscly like an action man but that wasn’t the case with me. I wanted to look quite thin if you look at the way the retail consortium have gone for example H&M promote quite a young boyish look and they call that a man look. That’s not stereotypical of the masculine man look that we’ve been used to. It’s only recently in the late noughties that’s been pushed through [inaudible 0.10.10]

For me I’ve always wanted to look thinner and for me to look that thin skeletal male look is normal. Whenever I say I want to feel normal that’s what I want to look like, I don’t want to look like a big action-man. I get annoyed when I read a lot of this research out there from these ‘professionals’ because they’ve read so much in their books that they believe all men want to look that way and all women want to look thin, it’s not that way at all, not for me anyway.
Gareth:

It’s interesting out of all the guys I’ve spoken to you’re the first one who’s used these pro-anorexia sites so it was just interesting getting your view on that. In terms of, going back to university, when you went to university where you at home or had you moved out?

Richard:

I had moved out into the university halls. My parents had lived in xxxxxxx and I moved to xxxxxxx. They had split up and divorced before I went to university so basically I had been on my own for years. You do hear a lot of stories of eating disorders that had the caring side and their mum and dad had always looked after them that’s not the case for me I had to deal with it all on my own. I had no help from professionals and I had no help from parents at home. The only thing I had going for me that got me through my disorders was my degree, university and my music

Gareth:

Music and education got you through it?

Richard:

Yes. I do feel a lot of bias towards myself and other adolescents that go away from home, have been able to manifest an eating disorder. The eating disorder doesn’t manifest itself. It wasn’t anything to do with the parental home situation to me. I didn’t have that anyway so all I had was myself.

Gareth:

I think from the point of view of researchers and health professionals there is a level of pigeon holing, so to speak. I won’t lie to you, the men I spoke to, I spoke to about 8 or 9 now, a lot have gone to university and because they have been out of that environment they are not used to things that have gone pear-shaped pretty quickly. It’s not a 1 cap fits all approach, nothing is. While we’re talking about your family background, again this is something I’ve asked everyone, your family background, is there any history of weight problems in your family or mental illness in your family?

Richard:

My uncle had schizophrenia and that’s on my mum’s side. My dad’s suffered from depression and things but with me, for example, I get annoyed because people automatically pigeonhole people who have anorexia with depression as well. I don’t ever
class myself as having depression. I’m too happy a person. Yes I get my down days but
that’s not depression for me. I get annoyed when people pigeon hole me. So yes, there is
mental illness in my family. As to weight issues not really. My granny is quite large for her
size but again on my mum’s side, not really my dad’s side but with my mum and dad
there’s never been a weight problem there. We just come from a really poor family who
couldn’t really afford to eat meat, we were living on a shoestring budget and my mum
obviously went to the supermarket to get the cheapest which was pre-packaged foods for
a pound, where you could get pizzas and things. As a child we grew up thinking it was
great. I probably put a lot of weight on because of that. So I think there’s a lot of pressure
on parents who are working who don’t have much of a budget to buy those things. In
terms of the weight problems and stuff like that there’s not really anything.

Gareth:

In terms of your weight at 23 and a half stone. I’m not interested in BMI or anything like
that. In terms of your height how tall are you?

Richard:

5’11

Gareth:

5’11, OK. In terms of getting up to that weight was that

Richard;

That weight piled on in the period between xxxx and xxxx and then we moved, I’ve lived
all over xxxxxxx, I’ve never been in the same place for more than 4 years as a child. I’ve
always moved from mum’s or my dad’s place. I lived in xxxxx, xxxx, before that I was in
xxxxx, I had an ok life there we moved from XXXXX to XXXXXXX again and I had no friends
and I was at a completely new high school and it was difficult to settle in so the weight
piled on. I used to isolate myself at home. I was bullied at school as well.

Gareth:

Do you think there’s anything in your background, again in your opinion, in your
background that you would say is why you got an eating disorder in the first place. Just
purely what you said in terms of getting to a certain weight, trying to lose weight and
then all of a sudden you just lost control

Richard:
An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

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No I don't think it's as simple as that. I think there's lots of things that just happened. I'm quite perfectionistic and am quite OCD with cleaning. Before even having an eating disorder that sort of period xxxx-xxxx my OCD and cleaning got worse, a way of masking out the problems at the time. Eating crisps, not with my hands, but with a fork and crazy things like that.

Gareth:

Oh I bet that was difficult, eating crisps with a fork

Richard:

Yeah and then I'd have to wash my face straight after it or stupid things like that, I'd clean skirting boards to 2 o'clock in the morning. I think that was there beforehand. In my childhood I was raped by my dad's grandfather and that's something I've tried to block away at the back of my memory but I think that has something to do with it as well.

Gareth:

Moving onto after university, when you actually collapsed, I take it that's when you sought help. I read with interest on your questionnaire that you've obviously struggled to get help. Quite specific on why. Can you talk through getting help and your problems with that?

Richard:

The first time I actually realized I had a problem was, I obviously scared about things beforehand. I collapsed in my bedroom in xxxxx xxxx, I was throwing up blood and peeing blood and I got taken to hospital. The next thing I remember was walking up in the bed in the morning and there was a team of doctors around me and they diagnosed me with anorexia, gall bladder problems and pancreas problems. They were more interested in sorting the pancreas and the gall bladder problems than the eating disorder. I remember being there, lying in that bed, thinking well they've given me this diagnosis, anorexia and the only reference I had of anorexia was Karen Carpenter and Hannah from Hollyoaks, a couple of years before that she had anorexia and they ran a storyline about that if I remember rightly. That was the only memory I had; I've never known a guy that has had an eating disorder. I didn't even know what it was. My Gall Bladder and Pancreas was in such a state because I lost all that weight in such a short period of time in such a drastic way. So they weren't interested in fixing the mental health and the eating disorder because I feel for them as doctors what they knew best was how to fix the physical. Rather than refer me to a dietician, none of that was done. They kept me in there for months in the dark, I remember getting frustrated and having...
looking it up online myself, male eating disorders, and I found the Men Get Eating Disorders Too Charity. I posted anonymously online on their forum for a couple of years before I eventually spoke out. I referred myself to the NHS xxxxxx. I was refused because I was a male and they had lots of females coming through. There was such a shortage of beds, despite the fact I was classed as nearly dead and they didn’t tell me that if didn’t go into hospital at the time I would have died.

Gareth:
Can you repeat that please?

Richard:
What part, sorry?

Gareth:
NHS XXXX said the amount of females.......

Richard:
There were more females coming forward for eating disorders. As a result they had very limited spaces of beds and as a result because I was male I would have to wait longer and that was a telephone call when I phoned up to chase up about the self-referral. I’d had enough about getting into hospital, finding out about this disorder through research and thinking 'I could die from this thing, I want to get help for it' and then I self-referred myself and then to have the door closed on me because of the bias of the gender, it’s ridiculous.

Gareth:
You can

Richard:
So

Gareth:
Sorry I’ll let you finish

Richard:
Sorry

Gareth:
I'll let you finish,

Richard:

Yeah, on the bias of gender it's ridiculous, I got annoyed and continued to post on the MEDGET forum. So without NHS support or parental support any sort of support at all to get through this eating disorder. I was doing music teaching and I wanted to get better for my pupils and for myself and my degree teacher at university, she got me through it just by being there, but I've never really had any proper medical help for it. I've just swung by the whole thing.

Gareth:

How do you feel as a man, you've not been able to get treatment because of the fact you're a man.

Richard:

I'm furious, I'm still furious to this day about it. Loads of males in xxxxxxx who aren't getting the treatment they deserve and their carer's and lots of them have died because their GPs [inaudible]. A GPs actually said 'The next thing you know males get eating disorders' and laughed in a parents face. So there's a lots of stigma and bias in xxxxxxx itself because we're such a xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx it's much easier because you've got access to more media and stuff. I guess there's more money spent in the NHS in xxxxxxx and xxxxxx, correct me if I'm wrong, in xxxxxxxx has very little limited budgets, that's the excuse I was given. I'm furious about it which is why I set the charity up, I felt I didn't get the help but I can make sure people do get the help that they deserve.

Gareth:

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Richard:

xxxxxxxxxxxxxxxxxx

Gareth:

OK I think I understand in terms from my own piece of mind. Is it like in terms of the thoughts of xxxxxxx, is it quite backwards in men don’t get eating disorders?

Richard:

It’s just in general. Male health is a taboo xxxxxxxxxx. I’ve been in xxxxxxx a couple of times and I notice how progressed it is there than compared to xxxxxxx. Although mental health in general in xxxxxxx is more forward than the rest of the UK according to the research I’ve looked at, but I think if you look at it from a health perspective the actual male gender is still falls short of the female gender if we are looking at gender in xxxxxxx on any health care issue. - mostly on mental health.

Gareth:

In terms of your treatment when you left hospital and you were told that you were basically you weren’t high up enough on the list, I’m assuming from what you said basically after that you’ve had no dealings with the health authorities. You’ve not had counselling or anything like that.

Richard:

I’ve had some counselling at university a couple of times, I didn’t think counselling was for me. I’ve felt I could have sat and talked to a brick walk about this stuff. I don’t feel it helps me at all. Looking at the types of treatment available and through research I’ve done, I would have liked to have CBT; I would have liked to see a dietician. Maybe I wouldn’t have had to go through 5 years of hell trying to figure out what was going on, still am in many respects but if I’d been given that early intervention, not even intervention. When I was at my worse they had the duty of care to help me and they failed that duty of care because of the fact I was a male and the health board have denied that claim to this day, which they will do because there trying to cover their own back [Inaudible]. There’s been a couple of news paper articles published in xxxxxxx newspapers even before I even had my eating disorder they had already said it as well.
But from late xxxx onwards the diagnosis of gap between those getting into inpatient treatment has seemed to improve slightly. But because the health board advertise as sort of female thing, if you look at the literature, the literature is the biggest part of the stigma in my opinion, when the girl has anorexia, the girl, the female, the woman they talk about the ovaries and things stopping, males don’t have that. So automatically through literature I’ve got a leaflet they hand out as health care. So automatically its telling GPs who are ill informed and members of the public it’s just a girls thing. So that’s why they just have girls coming to their door and the guys don’t know enough about it out it to go to their door. They guys don’t have that. Sorry about the rant there.

Gareth:

What I’m interested in is your opinions, what you think. You call it a rant but to me I think it’s great because you’re given me your opinion instead of your own narrative, this happened in xxxx, this happened in xxxx, you’re giving me your opinions and that’s what this is about, it’s about getting people’s opinions. The only way we’ll make change is to say this isn’t right, so to speak.

Richard:

Also there’s talk about barriers when it comes to eating disorders but I don’t think they ever touch the surface in my opinion the biggest barrier is the health care profession handing out a leaflet about eating disorders, and it’s a very female gender biased to the female gender. The way it’s written, the colour of that. All the things they don’t bother taking into consideration that will put a guy off from even touching it. It’s not that guys don’t want to talk about it, I’ve had all sorts of questions with professional ‘guys don’t come forward these days’, Well what do you do to get guys coming into your service as you have a duty of care to make sure they come to you. What measures do you take as a health care board to get the guys coming to your door. Don’t just sit and wait back for them to come to you, what are you doing to get them to come to you, that’s what you should be doing as a health board. The NHS is a people’s service. Why have people turning to private healthcare because not everyone can afford to have an eating disorder and afford to have their treatment. It shouldn’t be that way in xxxxxx. That’s the way it seems to be a post code and money lottery.

Gareth:

It shouldn’t be that way in xxxxxxx either, but it is unfortunately.

Richard:
We’re more rural here in xxxxxxx, there are more city links in xxxxxxx than xxxxxxx, in the xxxxxxx people go under the radar and die, that’s usually the way it happens.

Gareth:
The guys I’ve spoke to have been all across the country and I know to a certain degree what you’re saying is right, like saying xxxxxxx is more rural. The other guys have had huge problems in xxxxxxx. Can I just ask, I know I’m darting back, but the thinspiration sites, did you never ever consider you had anorexia?

Richard:
It never even crossed my mind; I never knew anything about it other than it being a girl’s thing. It never even crossed my mind a guy could get it. Maybe it was blissful ignorance I just thought there was proactive images helping me with glamorizing what I would look like perhaps. I never thought it was bad, in the initial stages. No, I never thought for a minute I had anorexia.

Gareth:
That’s really interesting. Moving onto another thing, another area. Relationships, basically in general. You said before with moving schools and so on and so forth it was a bit difficult making friends. How do you describe your friendships before having anorexia, I know you said you had problems with family. Were you isolated or anything like that?

Richard:
I was a little more mature than the children of the age I was, because I had to grow up a lot quicker because of the family situation we had. So when I moved all over the place I was the silent figure, the one that could never relax and follow the rules. As a child growing up, not all children are like that and I was always organized. I did have a friend or a cluster of friends but it was never the friendships you see everybody has or what you think they have, but I feel I was more mature than the other ones. Mentally I felt more mature than them because I had to grow up quicker. I had more adult like responsibilities as a child. I think that was the hindrance.

Gareth:
In relation to when you were actually diagnosed with anorexia how did the people you were associated with, can you remember, how they reacted to it.

Richard:
They were quite shocked. My friend at university, well my classmates had noticed the weight loss and they did comment on it just before I went into hospital, but to me still looked huge and could not see it when I was in the hospital bed after the diagnosis. A friend of mine visited me, she took a picture on her camera on her phone and looking at it from that phone first thing I could see what they were talking about, I was actually quite thin. They were kind of like we knew this was going on but nobody said anything to me about it. I feel had somebody had the courage to come up to me, I know it’s quite a sensitive issue, had somebody a month or two months earlier and said something, 'maybe I think you’ve got this' or 'maybe you should see a doctor, I’ll come with you'. Maybe just pledged that little bit of support in the initial stages that would have save me going into hospital and I wouldn’t have got to that stage where I almost died. [inaudible] (34:30) There was a friend at the time who told me it was self-inflicted and all my own fault and I actually believed that for a while. I thought that's what it was maybe it was all my fault. Initially I’d chose to lose weight and that’s what had happened. But then I looked back at it with the help of [inaudible](34:54) and I thought it’s not self-inflicted. So there’s quite a lot of people, including my brother said it was all self-inflicted. To this day my brother still thinks its self-inflicted, he can’t get the idea that it is a control thing and I have no control over it sometimes. It comes and it manifests I suppose but... a lot of them felt the fact the it was self inflicted.

Gareth:

Your brother thought it was self-inflicted, what did your other members of your family think?

Richard:

My sister was worried, she was ‘you just need to eat’ and (sounds like) feed me up which helped me put the weight on but it didn’t fix the problem. Others members of the family all thought it had to do with not eating by choice, but they just see it as I don’t eat. Some I think thought it was probably attention seeking it’s not like that at all [35:58 Inaudible]. It’s the stigma thing and the worst part of it I think because people preconceived ideas of what it actually is. They can’t see it through your eyes, they don’t have it. It’s quite hard for them to comprehend what it is, including the professionals.

Gareth:

That’s definitely true.

Richard:
“Professionals say ‘I know about it’, well you don’t know about it, you don’t know what it feels like, you’re not living this thing all the time. You’ve read it in a book; any numpty can read it in a book!” (Lines 426-28)

Gareth:

That’s true. How did it affect your living? When you was suffering, when you was trying to recover you’ve said that you was starving yourself, exercising excessively-

Richard:

I used laxatives as well.

Gareth:

You put on the questionnaire you were making yourself sick, using laxatives. How was that affecting your living?

Richard:

It became part of my routine really, I didn’t actually think anything of it I just thought... I hate to use the word normal, but it became normal for me. It was part of my life and part of my identity. Almost taken away stripped me of my identity. In fact I even changed my name (surname from father’s to mother’s), so changing that name once I had lost weight [inaudible] a new person. These things that I had had because of the eating disorder felt like a new identity a new person from the old fat Richard that existed the one that people hated and bullied. The new adult good Richard, I felt more people spoke to me so I felt quite euphoric. It gave me the life I had always wanted and never had. I suppose it made me feel like a new person, like the old person didn’t matter, didn’t exist. I felt happy, I felt if I had taken any one of them away it would have taken away the nice life I had been given.

Gareth:

I completely understand what you’re saying there. I completely understand that. I’m going to ask you a question about vomiting because it’s something some guys do and others obviously don’t do. So in terms of the vomiting is that something you found you were doing without any thought?

Richard:

It came quite; I remember being disgusted with myself and the disorder making me do it, I didn’t want to do it. [Sounds like but 39mins]. I hate being sick but that’s the worst thing about it. It’s the part I can’t explain to people I hate being sick and I actually feel ill, but
nobody likes being sick, let's face it, but to actually have to do it because of your disorder, it again became routine. In the initial stages it was horrible but the disorder was egging me on; it gave me that euphoric feeling. People are getting suspicious because you're not eating so if you eat people think you're normal. It's almost trying to be socially normal to normal to eat with them so I felt pressured to eat with them. I would eat with them but I could throw up without feeling guilty about eating it. And still maintain that normal identity that I had. The disorder made me feel if I was eating it would take that identity away from me and the old one would come back, the old me would come back, people would stop talking [to me]. Sorry, if I haven't answered your question.

Gareth:

Sorry?

Richard:

Sorry if I haven’t answered your question.

Gareth:

No you have, you actually have. Was that then similar with the laxative use?

Richard:

Yes it was, it was almost like getting the poison out of my body. Eating it just to make them happy. I think it’s fascinating looking back at to talk about it, it’s always trying to make other people happy. Even when I was larger everything I was doing was to make other people happy so I could be normal and fit in with them. It made me feel happy in terms of keeping the euphoric feeling to flush that out and be able to eat it. Then again I was craving the taste of food that’s what people don’t understand, being anorexic. I love food, I want to be around food, I prepare food all the time but I wanted to taste it, I wanted to taste it without having to put the calories on. After the disorder told me that I could still have this glamorous lifestyle almost, I use the word glamorous because that’s how it makes you feel like, on top of the world and you can get rid of the poison you are putting in there.

Gareth:

Obviously the interview is what we call semi structured and I’ve asked you different things to everyone. In terms of the effects of the eating disorder did you notice the effects on your libido?

Richard:
Again I’ve read everywhere, sorry if I’m having a rant here, but the research online says guys lose their libido but for me [had a much higher sex drive, being anorexic gives you the euphoric feeling, Gods knows where I was getting the energy from, but it gives you this ADHD energy, you know where your bouncing from the walls. In terms of the libido itself I had a high sex drive.

Gareth:

The reason for that is starvation the first thing your body does is shut down in obviously men and woman like the reproductive areas. Impulsivity. Did you ever notice you were more impulsive than before?

Richard:

I am more controlling and impulsive than before.

Gareth:

I’m sorry, controlling?

Richard:

Yeah towards other things. I have to be in control of something, like for example I have to make itineraries for everything, everything’s got to be a lesson plans it’s got to be almost be regimented in everything. Impulsive, in terms of the disorder or in general?

Gareth:

Just in general. The list I’m asking you is from research, what I’ve picked up. Like a lot talk about libido, impulsivity. Some of the guys I’ve talked to said ‘well I think I’m more impulsive’, others say ‘I’m not’. It’s not a 1 cap fits all approach. Me, I probably shouldn’t say it, but I’m impulsive. I went out and bought a car and a house, just like that just cos it fit the criteria. That was really impulsive. I’m still paying for it now actually. Impulsivity if you’ve got to think about it it’s not really impulsive.

Richard:

Let me explain that, because impulsive is an ambiguous word it could mean anything, from your research I’d say yes I’ve spent money on alcohol for friends and things like that. I was drinking the alcohol and going out on nights out with them to fit in. As you said with your car, I was doing lots of things. I would never have done that before. Before I went to university I never drank, again it was just a personal thing to fit in with them.

First time I felt socially, like, socially that I fitted in with other people, it didn’t matter.
what I looked like. I actually started worrying about what I looked but it actually didn’t matter anymore as it was more about me as a person. If that makes sense.

Gareth:

Yeah I think it does. Next one is did you notice any changes in your behaviour, again its fairly ambiguous because I don’t want to be accused as a researcher of trying to lead you into answers.

Richard:

Sorry, what were you saying?

Gareth:

I’m just saying in terms of any changes in your behaviour, were you a lot happier, angrier, were you short with people, and were you more aggressive?

Richard:

I was more aggressive, short with people. People would irritate me much more. If they weren’t on the same wavelength as me I wouldn’t speak to them, I’d be short with them, I’d argue with them. What they were doing with food and things was not what I thought were acceptable. I would have a big go at them and bring them down for it. Just in life in general if they didn’t turn up to university at a certain time I would disregard them, I would snap. Sleeping patterns, I became nocturnal, trying to switch off was difficult. Even now it’s still difficult trying to switch off. I was in running 90 plates at once, metaphorically speaking, of course.

Gareth:

Sorry, you’re in 90

Richard:

Spinning 90 plates at once metaphorically speaking, I was doing lots of activities like volunteering, all these music activities, trying to keep the social life up because I felt like to keep this thing going I had to keep busy and be out there and be proactive. So yeah, my behaviour changed lots. I went from being this person who stayed in the house all the time to being this extrovert person and doing absolutely everything and that I’d never done before. I even took marijuana and stuff at university things I would never have done.

Gareth:
With what you were saying about volunteering and so on and so forth, was that people pleasing?

Richard:

Yeah it was all people pleasing, to make people think I was a great thing, to keep this facade, this identity up that had been created by an eating disorder, although the part of it was me itself, it wasn’t actually who I was. It was painting multiple characters, who I was depending on the people and the social that I hung around with at that time. It was almost like putting a different face on for them.

Gareth:

Can I ask again in terms of your mental ability, again it’s fairly ambiguous, did you notice anything with that in terms of the eating disorder. Confusion, difficulty in making decisions, you get tired. Basically did you notice any mental problems in terms of decision making and so on.

Richard:

Nope, never been tired. I’ve always been very wired, if anything this disorder has made me more wired than ever before. Like I have to be constantly stimulated, I have to be doing something, reading a book or playing the piano or playing a few instruments or learning an instrument, I’ve got to be wired and kept I suppose academically enthused. I like to know everything there is about something, I’ve never been tired or found it hard to make decision. I suppose when the disorder was at its worse decisions weren’t actually mine and I remember it being a big blur.

Gareth:

Some of the effects, like starvation, you’d not eaten anything since at 2 o’clock in the afternoon, your falling asleep. Did it affect you at university, did it affect you if you were working and so on.

Richard:

When I was really thin, I’d find myself sleeping, after I came home from university. I couldn’t physically get the energy to move, I’d just sleep all night. In fact there were days I stayed off university and just slept for days solid in a row and I remember waking up one day thinking it was Wednesday and it was actually Saturday or something and then getting an email from the university to come in for a student disciplinary because I’d missed my lectures and stuff. It was almost like I’d blinked my eyes for a second to it and woke up to it again. I didn’t feel like I’d slept, apparently I slept for days on end. My body...
must have needed that, must have just shut me down like a computer, put me in sleep mode because I hardly had the energy. At its worse that’s what it was like.

Gareth:

That’s interesting; you’re the only guy who’s said more than anybody else about that, so thank you for that one. Do you mind me asking questions about sexuality?

Richard:

No I don’t mind.

Gareth:

I’m really interested in this because of the guys I’ve spoke to, I spoke to another guy who is gay and a guy that’s bisexual and the others were straight. Now the guy I spoke to who’s gay, he said some things that were like ‘wow, I’d never thought of anything like that’ so if you don’t mind, I’d like to ask you some questions about that.

Richard:

Sure.

Gareth:

In relation to sexuality before we start, has your sexuality ever worried you?

Richard:

Not really no. I wouldn’t say it did. More so because I came from a violent father and I thought he would disown me and stuff but the whole divorce strangely happened because my dad came out as gay and left my mum, I’ve got a gay dad; I’ve got a gay sister and a gay brother all off the same dad, so it’s a pretty confusing situation but it’s never worried me, no.

Gareth:

The reason why I ask that question is because in the history of male anorexia in terms of the writing, go back to the nineteen thirties when they first started writing it in terms of men it was basically it was gay men, it was a homosexual trait for want of a better word. Moving up to ... If I’m be honest with you, I’m heterosexual, straight, or whatever the politically correct term is, but when I first went to the doctor to get the literature you was talking about before, it’s female only or, it’s-
A gay man!

*Gareth:*

Yeah, and obviously you look at the literature and you look at the statistics and obviously it’s not necessary the case but it’s one of the things where the research has asked me about and again I’m being honest, I was single, not interested in relationships because everything was falling apart and I get this piece of paper that says most men who have anorexia are gay, I’d think to myself at that time am I gay, I’m a teacher well the kids think I’m gay, the staff think I’m gay, am I gay? I don’t think I’m gay but am I gay? So to speak so.....

*Richard:*

That’s the whole question feminine and masculine thing that tends to happen, the whole anorexia gay man thing, you look at the research of it and they try to feminise the gay man situation, and background and story, it’s never about ... for me it’s about what masculinity is. Means nothing nowadays, it’s all changed.

*Gareth:*

That’s one of the questions I want to ask. The next theme masculinity, in terms of your opinions of it, eating disorder is from a feministic viewpoint and then obviously the stigma of mental health and so on and so forth and it’s like a breakdown of masculinity and it interesting for your opinions on that.

*Richard:*

I’m of the belief I’m very masculine, I feel myself very manly and I don’t like the fact the fact that professionals try to portray it as a very feminine thing, a very feminine/gay man thing. I combine that together because it’s the only way they can get their head around it, the professionals. They link it with a feminine thing, so men who like men are obviously very feminine because that’s what they are therefore they try to feminize the gay man and the gay man’s background and that’s what puts the seed in other peoples head, the thumb print idea by Descartes, they now have that idea in their head that that’s what it is, so everyman man with an eating disorder has to fit into that femininised category, and what masculinity should be if that makes sense.

*Gareth:*

Yes

*Richard:*

Comment [AC112]: Masculinity - rejection of traditional views - especially feminisation of Gay men.

Comment [G113]: Masculinity – but unhappy how EDs are portrayed

Comment [G114]: Masculinity He personally rejects traditional views of masculinity, and believes that it is easier for processional to explain and understand EDs by masculising and feminising things. – I personally do not agree.
But it doesn’t work that way, not even for gay men. You read a lot of things in the paper and research books about guys who are close to their mums and stuff like that and that’s why they have an eating disorder and all that rubbish. I don’t think it’s anything to do with that. Eating disorders come hand in hand with the body image worries and woes which we all get, regardless of your gender or what it means to be male or female is one of the big attributes to it. I think there are a lot of pro-feminists things going on and there have been for past years but there are no equal rights when it comes to males, masculinity, and men in general. It seems to be ok to sell cartoon hero costumes in Asda and have 6 packs on them, if we were to put costumes of princess with their boobs hanging out of them or a high skirt with a pair of high heels and aim that at young five year old girls there would be uproar, because we are basically prostituting five year old girls, but it’s ok to give a five year old boy an idea that what masculine is having that six pack muscle, the whole thing man up, be strong and don’t show any emotion. That whole early 1900’s or even before that idea of what a man is when you compare it to a man showing his emotions. If a man showed his emotions years ago he was called gay even if they weren’t nowadays if a man shows his emotions and happens to have an eating disorder he is automatically feminised because it’s the only way they can get their heads around women have eating disorders so these gay men fit into that category, their very feminine, they’ve done it because they want to lose weight. [inaudible 58:28] It’s not like that at all. Sorry if I haven’t answered your question, I feel like I haven’t really answered it.

Gareth:

No you have, because again you’ve given me your thoughts and obviously I’m taping this which is something I forgot to tell you at the start, I apologize for that.

Richard:

I thought you was, I was thinking how is he going to remember all this.

Gareth:

Yeah, it’s in the literature that I’m going to record this but I should have told you at the start of the interview, I forgot to tell you, after about five minutes I remembered and I forgot to tell you again, obviously I’m recording the interview, I’ll go through, transcribe it and pick up on what you say. So it’s really, your giving me your opinions, which is really helpful. You said you think you are a masculine man. So can I then ask what is a masculine man?

Richard:
For me a masculine man is a guy who identifies as being a man for a start, so that's what being masculine means to me. I identify as a man because I feel that although I like other guys I am quite, I don’t see myself as being feminine at all. When you look at it I suppose feminine means you like, it’s really hard to describe. I identify as a man, I like shaving and stuff, it sounds stupid to me. I identify as masculine because I am a man. I like the muscular physique a man has, the body thing is to me what being a man is.

Gareth:

Some men have said 'I don’t like football so I’m a bit feminine'

Richard:

don’t like football either but it doesn't mean I'm any less of a man because I don’t like it.

Gareth:

I agree with you but that’s the stereotypical ‘Oh he likes football so he’s a man’s man’ ‘Drink ten pints, he’s a lads lad’ I’m on a rant now actually.

Richard:

Can I just answer your point now? We look at masculinity [inaudible 1:01:13] I look at, there’s the type of man as you said it’s ok to drink 10 pints of lager, the lager belly and that's what being a man is, speaking to people like rubbish, the shaved head type thing and then there’s also the man who is big, strong, lean, muscular one, the porridge oats man from Scotland, I don't know if you’ve seen that, the guy with the kilt and the six pack, that type of one. It’s never ok to be a thin, young man your seen as puny and you’re laughed at. You look like a boy even at aged thirty. But it’s ok we celebrate women’s body types of all types and sizes but what about men, we don’t do anything about that. That’s where we have a problem with masculinity I think.

Gareth:

We live in society where we talk about we’re all emancipated...

Richard:

We are all looking for women’s rights, but we forget about men.

Gareth:

To be honest I think you’ve hit the nail right on the head there. Can I ask again I’m going back; we’ve gone over the hour. Is it alright to have another five minutes of your time?

An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or a-typical anorexia/EDNOS

Gareth Lyons

Appendices
An exploration of the lived experiences of men who have an eating disorder in the guise of anorexia or atypical anorexia/EDNOS

Gareth Lyons

Appendices

Richard:

Sure

Gareth:

Thank you. It’s really in terms of I don’t know how to word this so I apologize if it doesn’t come out very well. The other guy I spoke to who’s gay he was talking about in terms of gay male society, sort of like having a hierarchy structure whereby younger men, pressure younger men to be a lot thinner and a lot more feminine.

Richard:

Sorry, can you repeat it.

Gareth:

Sure, basically the other guy who I spoke to in my study, who’s gay, he was talking about basically in the gay community there’s a hierarchy, a structure. Where young gay men there’s more pressure on them to be thinner, a lot in his words, a lot more feminine and less masculine and so on. Is that something you’re aware of?

Richard:

I am! But I totally disagree with that statement because that’s only if you feel you fit into and I use quotation marks here ‘a community’. A community if you look at the wording is a group of people that accepts lots of other people. I view the scene and not the community as being very exclusive and very cliquey, you fit into it. The hierarchy thing I agree with you, you fit into the slim feminine gay man, you fit into the butch, fat type of guy or the lean muscular one. But there’s no in between one. So you’ve not got those three but there’s no common ground between them and that’s only if you identify as being part of that scene. I don’t go into any of the clubs and things like that. I avoid all that. So yeah there is to an extent but only if you identify and go out actively seeking that community. I think the more you seek that community the more you become involved in it and you follow that clique. I don’t get involved with it. I know a lot of guys like that it’s not for them.

Gareth:

I didn’t know so I thought the best thing was to ask. The other thing was, again in terms of your sexuality. You spoke about sex drive, again the other gay man I spoke to painted this picture whereby he actually, whilst he was staving himself so to speak, and becoming this thinner person he was actually benefiting from a lot more promiscuous.

Comment [AC125]: Sexuality - Gay
Scene - accepts that the stereotype is the case, but rejects it in his life. So again he is a victim of stereotyping

Comment [AC126]: Sexuality - Gay
stereotypes have to buy into it.
Richard:

Being more active. Yeah I know what you mean; I was the same. It makes you feel more; you love yourself much more. When you go out you seek it because you [inaudible - 1:06:08] you can do anything basically or any anybody basically. So yeah I would agree with that statement.

Gareth:

That’s great that. Just got a couple more questions. Have you had any problems with work, with an eating disorder? It’s a simple yes or no.

Richard:

Yes

Gareth:

Sorry?

Richard:

Yeah.

Gareth:

Do you want to elaborate?

Richard:

I was working in a xxxxx xxxxxxxx as xxxxx xxxxxxxx and I had to handle and prepare food a lot of the time. The food part of it didn’t bother me, the routine did. I was expected to have lunch at this time, you must eat at this time and you must eat this portion because your work mates eat the xx meal deal it’s a xxxxxx and xxxxx and xxxxx. For a lot of people they don’t tend to eat lunch or people can’t fathom, even in recovery, who says you should eat three meals a day? It’s only government recommendations It’s not a law that says you miss a meal out of the three meals that day and it is the end of the world. But the minute someone knows you’ve had an eating disorder, you miss one of those three meals, particularly at work they notice that. If your off and your having a particularly down day and you have relapsed, your work, I found work wasn’t really supportive because they just seen it, as again it is a stigma thing, all in my head, self-inflicted, get back to work blah blah blah then you know you’ll be fired. You felt rubbish having to go back into work despite the fact that yourmentally well enough to be in work even physically I wasn’t feeling well as a result of it. But if I had cancer and it came back they...
would give me time off no problem because it’s a physical thing they can understand. Unless they’ve had an eating disorder or a mental health condition it’s quite hard for an employer [inaudible 1:01:15]. I think they need a legislation put in place to protect the employee at work who has a mental health problem and protect that characteristic when it come the equalities act in my opinion.

Gareth:

Agree with you on that. I know you spoke about charity, you spoke about Men Get Eating Disorders. Have you had any dealings with Beat?

Richard:

No I only just recently spoke to them. I looked at their website years ago when I was ill I didn't feel it was right for me. When I looked at the website and it was women hugging women, pink colours, it wasn’t right for me. I was wanting information about why a guy has it. I felt Men Get Eating Disorders Too at the time was right for me. But then again everything is all xxxxxxx and xxxxxxx, xxxxxx and xxxxxx. Sorry I keep harping on the xxx thing, I’m not an xxx fan at all, the national state thing, I believe in the xxxxxxxxxx. There is a sense in xxxxxxx that there is nothing here for us, unless you create it yourself, there's not going to be anything. 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guys I spoke to from different parts have said similar things. In terms of MENGET it is a very small charity and xxx is in Brighton so it’s very Brighton-centric.

Richard;
I agree. [Inaudible 1:11:14] a lot of work is being sourced to xxx it’s very xxxxxxx. That’s not what the charity should be about. Xxxxxxxxxx xxxxxxxxxxxxxxx xxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxx. But MENGET they get a lot of money so they spend the money in the one area of England. Xxxxxxxxxxxxx xxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxxx xxxxxxxxxxxxxx in fact I going down for the conference in July and I will bring it up again. I do feel MENGET is very hungryesc (?????) it’s not willing to work with other... It does work but it does in xxxx way, xxxxx being going behind their back ) xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxxx. But MENGET they get organisations who have similar values, but it seems to be MENGET is the UK charity but you’re not a UK charity, you don’t seem to do enough work in your remit. So yeah I do agree. Beat and MENGET have a lot of personal history as xxxx use to work for Beat before xxxx xxxx XXXENGET up there’s a lot of conflict going on there, if you don’t agree with the conflict that xxxx has with them and they have with xxxx then you get dragged into it. I can’t be bothered with that and a lot of organizations people can’t be bothered with that you come in to help people, not get involved with politics.

Gareth:
That’s definitely true.

Richard:
They get a lot of money thrown at them, both those organisations and It’s quite hard for any other organisations to use the funds in their local areas to give it out to help them.

Gareth:
Again I’d largely agree with you. You’ve had more dealings with charities than I have, so it’s fair to say in terms of the charities you think they could do a lot more, being more UK specific?

Richard;
Beat have one ambassador, xxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxxx xxxxxxxxxxxxxxxxxx is brilliant at her job and she’s good, she’s doing it alone and with limited money, 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normal people going about their daily lives that have told their stories, getting buttons for money, absolutely nothing they’re getting for it. You can potentially damage and ruin someone’s reputation by putting something out there. But the actual disorder itself they sensationalise it, it’s all about the bones showing. When I did it they wanted pictures of me at my illest, when I was ill the last thing I wanted to do was sit and take a picture of myself in a hospital bed thinking the xxxx xxxxx might need this in 2013. I didn’t think of that and the women looked at me when I said that (His answer to a reporter). I didn’t sit in a hospital bed thinking I’m going to take pictures of my skeletal bones as xxxxxxx xxxxx might want this for an [inaudible] documentary. When I did all that they got the pictures they got, I showed them a picture of me in hospital but that was at a recovery point and that’s all they got. I just didn’t want to show any images like that because that’s not mental health, that’s not anorexia. That’s the wrong image of anorexia to put out there, it’s the wrong image about eating disorders. Eating disorders, yes are about foods to some extent but it’s a mental health condition first and foremost and it’s not focused on that. They mention some of it. When they interview you they never ask how you’re feeling, what thoughts were going through your head, what were the triggers or anything like that? It’s all about ‘so you were this weight and that weight’ and ‘oh my god that’s such a lot of weight you lost’. One of the headlines they quoted me with, the xxxx xxxx magazine was xxxxxxxxxx xxxxxxxxxx [sensational headline which would identify Richard] that was the headline. I was fuming at that. The image of a xxxxxxxxxx xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx [inaudible] makes it horrible. The headline was, the picture they put in they did exactly that the xxxxx xxxxxx picture was huge of me at my largest and then this small picture of me at my smallest. [1:18:48 Inaudible] But seems really important to the story of his media experience. It was the xxxx Newspaper that did that. They have a tendency to glamorise the disorder. I was rejected by one paper because my images weren’t revealing enough, despite the story I was telling. I don’t want to use the word story. My experience I was telling was personal to me. They didn’t care about that, they wanted a headline grabbing story to glamorize pictures of my bones sticking out. I wasn’t prepared to do it and I still won’t do it. I would actually sue a newspaper if they did that. Sorry, if that didn’t answer your question.

Gareth:

No you answered the question perfectly because that’s your opinion, I asked what you thought. The question was how do you portray and you’ve said as a mental illness it shouldn’t be glamorized. It should be portrayed as deadly serious.

Richard:
They glamorized cigarettes once upon a time and alcohol once upon a time. Now there's been millions of deaths from it they've stopped all that, they've put screens up against that in supermarkets, but where do you draw the line? I do feel sorry for the media in some sense because they are in a catch 22. Eating Disorder charities are quick to harp on about what you’re doing is bad! Well actually produce some media guide lines which actually work with the media and produce the guide lines. Don’t just use the charity and say this will be your guidelines like Beat have done and MENGET have done.

They never once worked with the media and asked them what they thought about it. It’s a two way system, if you want them to report on these things you have to be clear from the offset with them, xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx it’s not about them handing you a contract what they want out of it, it’s about what you get out of it as well. People are always quick to blame the media. But all the media have to work with is sensationalized images and that’s what the newspapers are going to get and that’s what they feel they are going to get. If we can lead the way helping the media, create good stories then there won’t be this continual argument. I feel like it’s almost a blame game. Like eating disorders charities no matter what charity it is, cancer charities, they want something to blame. They choose media because it’s the quickest thing to blame. If you’re going to survive as a charity or organization you want to help these people get the awareness out there they have to work with the media, otherwise the media will close all the doors and access and you won’t get any of it and you will be stuck in the same situation.

Gareth:

That’s true. I suppose the last thing I want to ask really is looking back what sticks out the most, in terms of your eating disorder experience, what sticks out most to you?

Richard:

It’s changed my life, changed it for the better and also for the worst. I now have loose skin as a result of losing all that weight and once again I won’t get any help for that but I have to save money to get rid of that. I’ve got problems with my teeth because of the throwing up and eating side of it. There’s not a minute goes by I don’t feel conscious about how I look. I’ve now been diagnosed with body dysmorphic disorder on top of it. In some sense it’s given me this identity but now it’s given me this identity that’s given me all of these consequences as a result of this identity and I don’t ever feel normal every time I walk down the street, I can’t describe it, I feel like I’m going to pass out because I feel conscious of people staring at me on the bus. Bringing all that anxiety back from years ago. It’s not fat anymore, its skin I’ve replaced it with, so I feel like the whole cycle has come all the way back and I’m back at point I’m lumbered with all these problems on
top of that. So I almost feel like body image wise I don’t feel a hundred per cent happy. I think if I could get rid of all this skin I think my eating disorder will diminish itself and I’ve said that to them but I still don’t get any help [inaudible]. Although it’s given me this great thing I’m a much more confident person. I’m back to square one again I live half the life I should live.

Gareth:

Is there anything that you want to add that I haven’t asked; is there anything you think I’ve missed?

Richard:

You’re just looking at the experiences of men with eating disorders not boys as well?

Gareth:

I mean obviously there is research with boys, there is really no research in terms of men but if there’s something you want to share feel free to share it.

Richard:

I don’t feel there’s enough done about the transgender type and living with it, being a man living with it and suddenly transitioning to woman and all of a sudden... I feel would tie in with your research because looking at the gender stereotype between the male and female that would blow it out of the water. that’s a side argument for your whole PhD, I feel it’s important to mention because maybe that’s key for making professionals understand exactly eating disorders, it doesn’t matter what sexuality you are there is a common link there, gender identity plays a humongous role in someone’s disorder being developed and I personally believe gender identity plays a huge role in an eating disorder, body image or exercise disorder.

Gareth:

That’s certainly where sexuality comes in. It’s interesting did you say that transition in male from female.

Richard:

Gender identity plays a humongous role in someone's disorder being developed and I personally believe gender identity plays a huge role in an eating disorder, body image or exercise disorder.

Comment [G161]: Looking back at ED

Comment [G162]: Looking back at ED – he is more confident, outgoing due to the weight loss but has he just swapped one set of problems for another – almost a new coping strategy.

Comment [G163]: ED manifestation – he believes gender identity a problem, yet why then did he have one – when he was never concerned about sexuality or masculinity.
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But everyone talks about their OCD and perfectionist tendencies, they are quite easy to talk about it’s just the mental health strand of it. The eating disorder strand of itself when I look it stems from the personal identity and sexual orientation identity but also the personal identity it’s a mix of that like a Venn diagram that’s the way I think of it.

Gareth:

It’s interesting because I did get an email from, I don’t know whether it’s a guy or a girl, in terms of asking them about transgender, and why I wasn’t looking at transgender. Over the weekend I was looking up on new studies from the last twelve months, there’s only three in the ED journal’s I looked at specific in men but there was two or three specific to men transgender. Something maybe is being looked at more what maybe people think.

Richard:

It’s the new fad of eating disorders isn’t it, to look at that. What can we generalise and sensationalise, sexualise, not sexualise make it seem sexy about eating disorders. It’s all about trying to think about a new image for it, how we can portray eating disorders a bit better. It’s like the new thing although there is more discussed about it, I don’t feel it’s looked at, even xxxxxxx doesn’t feel it’s looked at.

Gareth:

What I’m talking about is academic research, certainty two or three. I’ll tell you what I’ll do, not tonight, I’ll forget but I’ll write it down, I’ll have a look at the journals. I don’t know if you’ve got access

Richard:

I’ve still got access to my university account.

Gareth:

There’s three eating disorders journals, There’s the European, I’ll have them email you, I’ve forgot. I’ll email you the links to the articles, if that’s alright.

Richard:

Sure.

Gareth:
Then you can pass them on, they might be of some interest. It’s unfortunate, in relation to the study I’ve said any men over the age of eighteen couldn’t care less of if you’re a man and the person that emailed me about transgender, I said I’ll happily talk to you if biologically you are a man but the reason I’m looking at men is because people have looked at gay men, might have looked at black men but not looked at men in general. Instead of looking at narrow areas, let’s look at the whole area. Obviously by looking at the whole area I can ask more people, or more people qualify for the research to ask and then hopefully then I’ve done my research other people will take it on and say look, he’s picked out some interesting experiences there, let’s let look at those and like that, that’s why men.

Richard:

I understand. It’s quite interesting to me. Can I read the research?

Gareth:

Yes it’s possible as you’ve took part and once it’s passed the PHD if it’s publishable quality and all that, touch wood, therefore there’s no issue with it. Couple of other guys I’ve spoken to have expressed interest in having a look at what points came out. There’s absolutely no problem with you getting a copy of the research. I don’t know if at this stage, I’ll email the whole thesis out. I don’t know at this whether I’ll email people or do a small report, I genuinely don’t know. Certainly will make that available to people in the study and anyone else who’s interested. That won’t be for twelve months.

Richard:

I can understand.
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