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Disappearing in a female world : men's experiences of having an eating disorder (ED) and how it impacts their lives

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<http://dx.doi.org/10.1080/01612840.2019.1576815>

Title	Disappearing in a female world : men's experiences of having an eating disorder (ED) and how it impacts their lives
Authors	Lyons, G, McAndrew, S and Warne, T
Publication title	Issues in Mental Health Nursing
Publisher	Taylor & Francis
Type	Article
USIR URL	This version is available at: http://usir.salford.ac.uk/id/eprint/51410/
Published Date	2019

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Introduction

Since the turn of the millennium the prevalence of male eating disorders (ED) has increased dramatically, with admissions for men diagnosed with anorexia to specialist inpatient units within the UK rising by 70% since the year 2000 (Marsh, 2017). In 2012-13, 160 men were treated within inpatient units for anorexia and atypical anorexia, approximately 7% of the total inpatient population (N.H.S Digital, 2013). However, these figures do not account for; men within the various health services in the UK who have not been treated as an inpatient on a specialist unit; the issues men face in getting diagnosed with EDs, due to the previous restrictive guidelines for men in DSM IV (Freeman, 2005); or the numbers of men who do not seek help. Evidence suggests stigma associated with EDs results in the number of men with EDs being considerably higher than that in published statistics (Copperman, 2000; Duker & Slade, 2003; Soban, 2006). Likewise, it has been argued that low numbers of men with EDs present to health services due to stigma and ignorance (Cooperman, 2000; Soban, 2006).

Traditionally the ratio of males with an eating disorder was estimated at 10% of the total ED population (Wolf, 1991). However this figure has been challenged by more recent research, evidencing a ratio as high as 25% (Skolnick, 2014). Within the UK it is estimated 1.25 million people are experiencing an ED, with between 10 and 25% being male (Beat, 2017). Statistically around 40% of people are diagnosed with bulimia and 10% anorexia, with the remaining 50% having Eating Disorder Not Otherwise Specified (EDNOS). The latter includes all those diagnosed with anorexia and bulimia who did not fit into DSM guidelines or who had a binge eating disorder, not recognised pre DSM V (2013) (Beat, 2017).

Within the literature, there has been a strong focus on EDs in women (King, 2013), and a suggestion that men and women diagnosed with an ED share similarities in many aspects of the illness (Cooperman, 2000). However, males experiencing anorexia tend to have more gender identity problems, higher impulsiveness and a lower sexual drive than their female counterparts (Carotti et al., 2008). Likewise, it has been suggested EDs in men are associated with homosexuality (Jones & Morgan, 2010). Regardless of similarities and differences, it seems 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 (Brown, 2007; MacCaughelty et al., 2016). A number of researchers suggest a significant barrier for men with EDs accessing treatment has been from health professionals whose own views on masculinity exclude men as sufferers of an ED (Peat et al., 2008; Ousley et al., 2008).

In a review of the literature Jones and Morgan (2010) examined 77 research studies on the subject of male EDs, concluding that not one of the studies explored what it was like to be a man living with an ED. Furthermore, 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, how they cope with, or seek help for, distress. As EDs are recognised as mental illnesses those who experience them often face associated stigma, as well as the particular stigma of being a man with an ED.

Literature Review

In light of Jones and Morgan's (2010) and Ridge et al.'s (2010) findings, a literature review specifically focusing on research post 2000 reporting on men's experiences of living with an EDs, was undertaken. Database searches included Medline PsycARTICLES, PsycEXTRA and

PsycINFO, in addition to hand searching specific ED journals and the reference lists of those articles identified as appropriate to the study. In total 17 studies reporting of men's experiences of living with an ED were identified, however 13 of these were case studies, ten only focusing on one person. Four studies identified the lived experiences of men diagnosed with an ED (Cooperman, 2000; Button & Warren, 2001; Robinson et al., 2012; Räisänen & Hunt, 2014), but all were heavily focused towards their clinical experience. Button and Warren (2001) interviewed one man and a number of females, but when findings were anonymised they were not presented specific to gender and EDs. However, the literature review allowed a picture to be created of previous research and this was valuable in creating a thematic framework for undertaking narrative interviews.

John Doe – A possible blue print for male EDs

Evidence of specific traits

Drawing from the studies reviewed there appears to be a 'John Doe', or a stereotypical man diagnosed with an ED. The onset of the illness appears to be between the ages of 15-20 years old (Crisp et al., 2006; Lindblad et al., 2006; Gueguen et al., 2012), however it is unclear from the findings of these studies if this was the age when diagnosed, or the age when participants' themselves identified their ED behaviour starting. With regard to family background, Crisp et al. (2006) reported it is likely to encompass a history of parental obesity and/or mental health problems. A number of studies found men with EDs to be overweight prior to the onset of the illness (Cooperman, 2000; Strober et al., 2001; Fernández-Aranda et al., 2004; Raevuori et al., 2009; Gueguen et al., 2012), and the goal for weight loss was to become more "toned/muscular/athletic", as opposed to the female goal of achieving thinness (Cooperman, 2000; Núñez-Navarro et al., 2012). While Grossbard et al. (2012) support the findings of the

above studies they also suggest depressed mood is likely to play a prominent role in men with ED symptoms. Grossbard et al. (2012) further explain men focus on body and size with a drive for muscularity, linking it to masculine gender norms and the psychological and social benefits of achieving this possibly having a protective function from symptoms of depression. This could perhaps be a reason for Muscle Dysmorphia or Bigorexia.

Male ED behaviour: controlling the weight

As well as restricting food, a number of studies reiterate the use of excessive exercise as being a favoured method of men in weight control (Raevuori et al., 2008; Dissing et al., 2011; Murray et al., 2014; Younis & Ali, 2012). Other forms of purging are also reported to be used by men having an ED, with vomiting being favoured over laxative abuse (Núñez-Navarro et al., 2012). However, Núñez-Navarro et al. (2012) acknowledge debate in relation to this finding. Buchanan et al. (2013) found the opposite to Núñez-Navarro et al. (2012), although the former's sample was based on people who had been sexually harassed. In the UK Button et al. (2008) found men tended to vomit more than women, although these results were across the whole pantheon of anorexia, bulimia and EDNOS.

Masculinity and sexual identity

Masculinity has been identified as a barrier to 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. Courtenay's (2000) study on general health care and attitudes towards masculinity, found succumbing to, or seeking help for such illness are attributed to signs of femininity. Raevuori et al. (2008) also identified anorexia as

being perceived as a female illness, with three of the five men interviewed not disclosing 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 shame attached to this type of illness, may account for male eating disorders being under-diagnosed, untreated and under-researched (Räisänen & Hunt, 2014).

Sexual identity issues have also been identified as one of the potential triggers for anorexia, which in turn compromises 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"* (PG 166). Linblad et al.'s (2006) study concluded men with anorexia have lower inclinations to form close relationships, have sexual identity problems and asexuality. A number of studies have demonstrated a high statistical number of men diagnosed with anorexia as being homosexual. Bramon-Bosch et al. (2000) reported homosexuality among males diagnosed with an ED being eight times higher than their female counterparts. 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, suggesting men in the homosexual community are under much more pressure to look good than those in the heterosexual community. However, Fassino et al. (2001) suggest four out of five men within the ED population are heterosexual. Regardless of sexual identity, men who experience EDs are likely to have problems forming relationships (platonic and sexual) (Lindblad et al., 2006) and, as a result, are likely to be sexually inexperienced, unless they were sexually active before onset of the illness (Crisp et al., 2006).

Psychological wellbeing and mental illness

Research evidence regarding psychological wellbeing remains unclear. In terms of feelings about self, words such as “insecure”, “worthless” and “inadequate” are commonly evidenced in the literature, as well as a belief of having a lack control (Claes et al. 2012). The possibility of co-morbid mental illness is also reported as likely (Bramon-Bosch et al. 2000; Raevuori et al. 2009), with common psychological traits including; Obsessive Compulsive Disorder (OCD) tendencies, difficulty with decision making, impulsivity and/or immaturity (Fassino et al. 2001; Raevuori et al., 2008; Tchanturia et al., 2013). A man diagnosed with an ED will show more anti-social behaviour than his female counterpart in terms of lower levels of seeking approval and more bouts of rage, as well as being less compliant and cooperative (Fassino et al. 2001; Núñez-Navarro et al., 2012).

While the findings of the literature reviewed present a blueprint or a John Doe of a man who experiences an ED, it also highlighted the need for a study which would better explore and embrace the complexities of human experience of living with an ED (McAndrew & Warne, 2010). The research presented in this paper adds to a limited body of knowledge regarding the experiences of men living with an ED.

Methodology

The aim of this study was to explore the lived experiences of men who have, or have had, an ED in the form of anorexia or an atypical variant, namely an EDNOS. The underpinning philosophy for this study was that of interpretivism. Interpretivism is concerned with subjective meanings which relate to how individuals understand and make sense of the world in which they live (Gephart, 1999). Interpretivists acknowledge 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 & Vidgen, 1999). As a result, in order to

collect the data they desire, interpretivists 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. Qualitative research, adopting an interpretivist framework and using narrative interviews as a means of data collection, was used for this study to establish mens' experiences of living with an ED in the real world.

Narrative interviews enable the gathering of peoples' stories as told by them with minimum restriction (Etherington, 2011). It is the primary form by which human experience is made meaningful, by organising experiences into temporally meaningful episodes, allowing people to express emotions, convey beliefs and make sense of events in their lives (Fraser, 2004). Narrative interviewing should not only take account of what is said, but also of what is not said, both in the context of the lived experience and within the context of the interview, where representations of the lived experience are expressed verbally and non-verbally (Josselson & Lieblich, 1995). Likewise, account of the subjectivity of both researcher and participant needs to be acknowledged, as lived experience is often structured in accordance with cultural forces, providing insight into the way in which those forces operate within the individual's life (Lacan, 2003). Using narrative in this study facilitated men, who had direct experience of EDs, to express and contextualise their own stories in their own words.

Ethical and Moral Considerations

Ethics approval was granted by the University of XXX (HSCR 14/13). As with any study dealing with emotive issues, not least the distress that might be caused by the interviewee sharing his story, needed to be considered. 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 debrief was not recorded and formed no part of the research. Additionally, if

needed, each participant was offered a list of contacts where they could access further support if required.

Participants

Purposive sampling was used for this study, allowing recruitment through the ED charity *Beat* who advertised the study on their website, mailing list and through social media, directly targeting people who were able to participate. Inclusion criteria were males, over the age of 18, who spoke English and had been diagnosed with an ED or who thought they had experienced the illness. In total 14 men responded to the advertisements, 13 met the inclusion criteria and were sent a study outline, a short demographic questionnaire and a consent form. Nine men arranged an interview, with one man dropping out pre-interview on medical advice, and another not meeting the criteria. In total seven men were interviewed, five via the telephone, one via email and one face to face. Interviews lasted between one and two-hours. Narrative research can be conducted using a small number of participants (Squire, 2013), as the information being collected relies on depth rather than breadth. Furthermore, the quality and richness of the data is of essence and there is no fixed sample size in narrative research, particularly, as in this research, when the aim is to understand and describe a sensitive topic (Holloway and Freshwater, 2007). The men's ages ranged from 23-34 and geographically they were based in England (South West, South East, East Midlands, North West), Scotland and Wales.

Data Collection

Each participant was asked to complete a short demographic questionnaire before being interviewed. Narrative interviewing, using a quasi-biographical approach based on Wengraf's

(2004) description of a full biographical interview was used. Participants were asked a single question about a theme identified from the literature review, which they answered without interruption, the researcher using follow up questions for clarification and to explore deeper meanings.

Data Analysis

All qualitative analysis involves interpretation, and although analysis per se is often considered a reductive process, interpretation is a broadening process used to make sense of existing theory whilst building new insights (Freshwater & Avis, 2004). Sense making that leads to meaning is attributed to specific situations and mediated through the inter-subjective encounter inherent in the research process, hence the opening up of any text to alternative interpretation (Frosh & Emerson, 2005). However, in terms of qualitative research being credible, selected elements should stay close to the participants' own material and interpretation should be made in such a way that makes most sense at that given moment in time (Midgley, 2006). In this research each participant's story was transcribed and analysed as a whole for emergent themes and sub themes. To ensure authenticity of the men's narratives, each one was examined and the text coded using headings related to the broad themes the interviews were based around and those that arose during interview. The researcher interpreted what appeared to be important themes organising these into a logical order, whereby each man's narrative of his ED was created.

Following this process an analysis across the seven narratives for common themes was undertaken. For each interview comments and quotes pertaining to what appeared to be the same or a similar theme were placed under a main heading, allowing the composite 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 together with researcher interpretation to add meaning. The second element of analysis was to compare and contrast the men's stories and seek shared experiences. Presented in this paper are the common themes from the men's stories which in the discussion section are referenced back to the existing body of knowledge.

Findings

The Demographic Picture

(INSERT FIG 1 HERE)

Figure 1- Demographic Participant Information

The demographic data, presented in figure 1, provides a snapshot of the participants. The two gay participants used more methods of purging than the straight/bi-sexual men, perhaps exemplifying the objectification theory in gay society (Brown & Keele, 2015). A further illustrative example of the evidence regarding 'high achieving' associated with EDs is seen in the men's educational attainment. Five of the seven men had at least a graduate qualification, of the two remaining men, one had attended university, but left due to the effects of anorexia and the other, at the time of interview, had started to study as a mature student for a graduate qualification.

Narrative Interviews

Four themes were extrapolated from the men's stories: (1) The Final John Doe, comparing and contrasting generalised information from the literature review regarding the stereotypical man diagnosed with an ED. (2) Help! I Need Somebody – Bedlam Revisited, explores the men's journeys into and through treatment and interactions with their families

and charity organisations, encompassing accessing and receiving treatment, gender inequality, role of loved ones and ED Charities (3) Masculinity - The Beast in Me, highlights some of the issues and paradoxes relating to being a man, including stoicism being strong, judging masculinity and no man is an Island (4) Not Working 9 to 5, encompassing issues and experiences faced by the men in their working lives.

Theme 1 - The Final John Doe

The men's stories and demographic data presented show many similarities to the stereotypical man diagnosed with an ED, 'John Doe', identified within the literature review. The age of onset of the illness was 15-20 years (Crisp et al., 2006; Lindblad et al., 2006; Gueguen et al., 2012), six of the seven men described being overweight pre-onset, and all of the men identified parents with either weight or mental health problems. With the exception of one man, all identified as being isolated growing up. The man who did not experience isolation was the oldest man at age of onset, starting to experience anorexia when trying to lose weight after giving up smoking. In contrast, the EDs experienced by the other men were triggered by a need to *'fit in'*. Perhaps the biggest difference from the 'John Doe' identified in the literature review, was the higher prevalence of gay/bi-sexual men, with two gay men and one bisexual man taking part in this study. This accounted for 43% of the participants as opposed to Fassino et al.'s (2001) 20% and Räisänen and Hunt's (2014) 30%. This difference could be explained by way of the stigma associated with ED's in men and it being 'easier' for gay/bi-sexual men to come forward and seek help and being more active in related social media/recovery groups.

Theme 2 - Help! I Need Somebody -Bedlam Revisited

Accessing and Receiving Treatment

The men's experiences of seeking help, their loved ones and treatment, formed a significant part of their stories. Six of the seven men presented to their GPs, four as adults and two under 16 (who were taken by parents/guardians). All were referred for further examination and treatment, indicating more awareness on the part of GPs as that found by other researchers (Treasure, 2005; Ousley et al., 2008; Peat et al., 2008). However, from this point their experiences differed greatly, reflecting that of the much maligned 'post code lottery' evident in England. John for example, living in an area with specialised ED services, found himself seeing an ED specialist within three months of diagnosis. In contrast, Stephen (a minor at the time) had to wait ten months, and Alan had to wait two years, even though he lived within a 20 mile radius of a specialist service. Richard was the only participant whose first treatment experience was not via a GP. After collapsing and being treated for physical ailments in hospital he found he could not get NHS treatment for his ED as he was deemed '*not serious enough*' after discharge. Russell felt 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;

"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. They came early [45 mins] 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).

It was apparent in the men’s narratives they felt 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, believing that although their BMI was classed as *‘normal’* upon discharge, they had not been offered support in dealing with the underlying issues related to their ED. In relation to treatment the notion of *‘relationship with self’* needs to be considered. A number of participants identified they had got better because they wanted to, indicating the importance of the relationship with self, and raising the dichotomy of re-feeding versus psychological support. Without re-feeding the mind will still be in a weakened state to want to get better, but without the mind wanting to get better it will not accept re-feeding or what is considered the achievement of a *‘normal’* weight.

Gender Inequality

There were a number of instances where the men were treated in a discriminatory fashion because of their gender. Whilst accepting this may have been unintentional, it still led to questioning of self. One of the men justified the discrimination, commenting on *“2000 years of patriarchy”* (Kevin), indicating an acceptance of being a second-class citizen in terms of being a man with an ED. One man experienced official *‘health’* communications which referred to him using female pronouns, while a number of the men commented on being given worksheets and questions tailored to females. One man had a period of in –patient treatment on a specialised unit, which had a female and disabled toilet, but no facilities for men. Group therapy was also an issue for some of the men: Stephen felt that he could not

share information being the sole male in his group, whilst Kevin felt marginalised when in a session on self-care, the therapist giving 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). Kevin stated *“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 *****”* (Kevin). Similar issues of female orientated care have previously been identified (Robinson et al., 2012). These concerns over existent gender bias with regard to treatment is an important issue, as the prognosis for men may be compromised if the health care they receive has the potential to further emasculate them. What was clear from the men’s stories was the relationship with their therapist was crucial to recovery. A number of the men had experience of different therapists and therapies, finding they made progress with one particular therapist’s style as opposed to another’s. Russell illustrated this when he spoke about changing dieticians/nutritionists

“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)

This again illustrates the problematic nature of adopting treatment predicated on a ‘one cap fits all’ approach as different styles work better with different people.

The Effects of Loved Ones

The relationship the men had with their families was both positive and negative. A number of men were able to control their ED at home, but lost control when going to university. In this instance the role of loved ones is unclear as to being positive or negative. Hiding behaviours in front of loved ones would seem to allow the behaviour to become entrenched, resulting in the *'swift decline'* as described in some narratives. However, at the same time loved ones appeared to enable the men to maintain a level of health and functionality, which was compromised when they were separated, such as going to university. In addition, at the time of his interview, Michael was in a relationship and he spoke of his desire to *'not experience his ED again'*, as he did not want his girlfriend to *'have to go through it'*. Protecting others from the emotionality inherent in some illnesses is a common phenomenon (Lee & Owens, 2002).

ED Charities

All of the participants in the study were recruited via adverts placed by *Beat*. A number of participants were active within ED fund-raising/activism/charity work, and the negative comments aimed at the ED charities within the men's narratives were surprising. *"I just see lots of photos of happy young women, it's all a kind of stereotype that kind of stuff"* (Henry). Whilst the men felt that *Beat* did some good research, they were dissatisfied with how *'corporate'* the charity was. Participants' believed it lacked a male ED presence, the website design was female orientated (which has now changed) and its fund-raising activities inappropriate. For some of the men the latter appearing more important than helping the individual, compromising its underlying philosophy. Richard was the most vocal in his criticism of *Beat* calling the charity a *"money whore"* (Richard), but he was not on his own with his

dissatisfaction; only Stephen did not make any negative comments. Other examples of the participant's concerns included; Alan being upset with *'its commercial tie with the then big sized clothing brand Jackamo'*, and also feeling *'exposed to inappropriate questions'*, in a media interview which *Beat* had set up for him, but did not follow their media guidelines. Russell identified 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'*, the result being he chose not bother.

Four of the men in the sample had experience of 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 England commented that they felt the charities were too 'Southern England' focused, and none of the men had engaged with an ED charity prior to their diagnosis. The latter suggests charities attempts to raise awareness of male EDs have not been successful. This was summed up by Kevin who 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).

Theme 3 - Masculinity - The Beast in Me

Stoicism Going Strong

The men's relationship with masculinity was complicated and perhaps, although speculation, no different from many other men. In the main the men interviewed verbally rejected traditional masculinity, yet their behaviours indicated many of the stereotypical traits associated with it. For example, four of the six men who were diagnosed over the age of 18 claimed they had no inclination that their behaviours were that of an ED, and only went to see their GP as *'a last resort'*, perhaps indicating a level of stoicism and/or denial/ignorance

of the illness. Alan, Henry and Kevin all spoke of the shame they felt being ill and Stephen stated he did not tell anyone of his illness due to not wanting their 'pity'

"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).

"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"
(Henry).

Judging Masculinity

There were high levels of educational/work-based success across the participants' narratives, illustrating their desire to achieve and compete. It could be suggested, masculine competition can be seen in the way the men fought their own bodies when engaging in their ED behaviours, as in order to be 'successful' in their anorexic behaviours the men had to be self-willed, disciplined, and competitive, even if it was against their body/minds protests. In addition, a number of participants perceived their lack of masculinity through their inability to enjoy or play contact team sports. *"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). Football in the school playground is recognised as a way of creating masculine domination and hierarchy. When football is not allowed, schoolboys find other ways to gain popularity and prestige through other physical and athletically competitive games (Swain, 2000). For the men in this study this was not the case.

No Man is an Island

With the exception of Russell, all of the men appeared to be sexually isolated, in both a physical and platonic sense, before the onset of their ED. The effects of the ED further emasculated the straight and bisexual men, with two of the straight men not experiencing sexual relationships before the onset of their ED. 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.

“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).

This illustrates Connell and Messerschmidt’s (2005) refinement of the former’s original theory, showing the different levels of masculinity, and how on a global level their sexuality and ill health bars them from hegemony, however on a local level they fulfil hegemonic criteria.

Theme 4 - Not Working 9 to 5

The final theme from the interviews relates to the men’s working lives. Adults spend a large part of their life at work and there are many pressures, especially financial, on a person to be in work, and therefore it would have been remiss not to explore this aspect of an adult’s lived experience. The employment experiences of all of the men interviewed had been affected by their ED. In some cases this had been through worrying about the ramifications of disclosure of the illness on application forms. The men who did disclose encountered varied reactions. When Kevin, who worked in the public sector, told his employer of his illness he

said;, *“they chose to almost immediately double my responsibility which was not just doubling my team, but taking on some quite difficult management”* (Kevin). After taking unpaid leave Kevin’s dissatisfaction was compounded when he tried to go back to work, and was told by his employer that they could find no reason to stop him coming back to work rather than being more positive about his return.

Two of the seven men changed career in reaction to the effects of anorexia. Henry had never worked full time because of his health, taking a succession of temporary jobs, which allowed him to have periods of recuperation. Richard, talking about his employer, stated;

“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. You felt rubbish having to go back into work despite the fact that your mentally 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.” (Richard).

Six of the seven men reported a decrease in their ability to perform their job due to a decline in their physical and mental state. Russell 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).

The one man who did not report such problems changed his career to one that was less well paid was less stressful. The men’s experiences demonstrated a need for further research in

this area, focusing on attitudes and experiences on the part of employers, as well as the question of competence and capacity in employment.

Discussion

The men's stories when compared with existing literature indicate many traits/characteristics which may be predictors of men with EDs. In gaining insight into the types of men who are susceptible to EDs it may be possible to identify people before an ED takes hold. Five of the seven men interviewed had no idea that their symptoms were related to an ED until they were diagnosed, however evidence suggests the longer an ED continues without treatment the worse the prognosis (Räisänen & Hunt, 2014).

The stories the men provided in relation to treatment and gender in-equality gives rise to concerns regarding facilities, attitudes and counselling materials set up for females only being discriminatory. A number of the men felt that stereotyping EDs as an illness of white middle class teenage girls (National Institute of Mental Health, 2014) has implications for those providing treatment, as well as those receiving it. The question of BMI being used as measure for diagnosis and subsequent treatment is not appropriate and although the focus has changed since the publication of DSM V (American Psychiatrist Association, 2013), a number of the men experienced problems due to BMI. Henry, Michael and Richard all experienced treatment issues as practitioners focused on achieving a '*physically healthy*' BMI as opposed to addressing their underlying psychological issues. Stephen was initially told he did not fit the criteria for anorexia due partly to his BMI not being low enough. Richard on the other hand was admitted to hospital after collapsing with organ failure due to his ED, and was understandably treated for his physical problems first, but at no point was he offered support for his anorexia. Upon leaving hospital he could not get support, due to the lack of services,

his weight gain and healthy BMI. Wooldridge et al. (2014) suggested that when the focus of treatment is on weight gain alone it can alienate service users as their underlying problems are not being dealt with.

A *'one cap all fits all'* approach is not the most effective way to treat EDs (Button & Warren, 2001; Colton & Pistrang, 2004). The continuation of such an approach raises the question of collaboration between the service user and practitioner within the treatment process. Whilst the men did not encounter any problems with their GPs as the first point of contact in terms of being taken seriously, there was differing levels of services available within trusts in different regions. The *'post code'* lottery has been highlighted for many illnesses and it is evident in the men's narratives, demonstrating they encountered very different pathways into, and experiences of ED treatment. Both Henry and Alan spoke of their frustration with treatment until they were able to get help from people they could identify with, while Russell did his own research to find practitioners whom he felt would be better able to help him. Some of the men experienced psychology/counselling whilst waiting for specialist ED services, however this was largely unsuccessful, 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.

The importance of loved ones in the lives of the men is an area which needs further investigation as there appear to be both benefits and potential questions. When living at home, loved ones acted as a buffer to the men. However, it was not clear if this was because the men did not control, for example, meal times or living at home reduced the opportunities for full restriction. Cooperman (2000), Weltzin (2005) and Räisänen & Hunt (2014) commented on the longer it takes for diagnosis the more ingrained the ED can be and the

more difficult to treat. In this situation it could be suggested being with loved ones make EDs more difficult to recognise and treat. It was clear in the study that when the men left home there ED behaviours quickly escalated and treatment followed, but if the men had stayed at home they might not have sought treatment as their behaviours could have been hidden or moderated. This leads to the issue of awareness of loved ones needing to be improved.

Raising awareness in society that men can become ill from EDs is paramount if attitudes are to change and health care is to improve. This is something that both the health services and ED charities should focus on in the first instance. Unfortunately, 18 years ago Cooperman (2000) raised the same issue; *“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 related 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 participants praised parts of what *Beat* and *MENGET* did, they still felt marginalised by *Beat* in terms of literature and their voices being heard.

Although awareness of men’s EDs is poor within society, employment law covers mental health discrimination. This study clearly shows there are questions which need to be asked and answered in relation to the effects of mental illness such as EDs in the workplace. Button and Warren (2001) highlighted that performance at work was affected for a number of the people in their study (35 female 1 male), whilst in this study all seven men indicated their performance at work had been negatively affected. Examining EDs at work was the subject of *Beat’s* collaboration with the Employers Network for Equality & Inclusion (2016), the resulting

publication being aimed at employers helping people with EDs or recognising signs of the illness. The latter is particularly pertinent to Russell, who terminated his employment which involved the safety of others, when he felt unable to function properly. However, the question which remains is the point at which he realised he may compromise peoples' safety. Considering the lack of knowledge of EDs within the men, as well as masculinity factors which can affect male self-care, Russell may have already compromised the safety of others. 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. At one level an employer would be unlikely to reject a person for a role and cite an ED as a reason due to this being discriminatory, but a growing awareness of mental ill-health may equally be responsible for the men's more positive experiences.

Study Limitations

Using a narrative approach can be seen as problematic as the information collected is subjective and temporal. Co-constructed interviews could have been used as this may have strengthened the men's stories by allowing them to see how their words were interpreted. However, this would have potentially diluted their stories. In addition to diluting the men's stories, co-construction was not used for pragmatic reasons of time and the study's aim of exploration of the men's lived experiences. Another limitation was the use of telephone interviews, where explication can be stunted, body language is absent and therefore cannot be used to give an indication of the emotionality of an answer, and prolonged researcher silences can lead participants to question if they were still talking to someone.

Implications of this study

The implications of this study relate to healthcare practice, employment, charitable organisations and academic research. Health providers critically examine their care provisions for men with EDs to ascertain if they are; fit for purpose (meeting the service user's needs), and if they are in any way discriminatory (buildings/paperwork/staff). Employers need to be aware of the issues specific to men with EDs, ensuring that their employees function in an environment that feels safe to share their mental health problems with the employer. This may be achieved by employers having equitable policies for those with mental and physical health problems. Whilst continuing their work, charities need to take account of the ED community as a whole, rather than showing bias towards those who have a higher prevalence. They are the voice for male ED sufferers and therefore need to work towards building better relations with their male users. With regard to future researcher topics for investigation should include; experiences of EDs in the work place; exploring constructions of self/masculinity within this group of people; and treatment narratives, the latter having the potential to impact on clinical practice.

Conclusion

While studies indicate a rise in EDs in men, there seems to have been very little qualitative research in this area. This paper has given a voice to seven men from a population who has largely been ignored. Published work regarding male specific EDs, with the exception of 2012, has remained at a consistent level of around three to four publications per year. It cannot and should not be denied nor ignored that statistically numbers of men within inpatient treatment is low, which may hamper funding. These figures can be misleading as they do not take account of men in non-inpatient treatment nor those who are not able/willing to seek help.

Social and professional stereotyping and stigma regarding 'masculinity' and having a mental illness often associated with women, may contribute to this situation, and will only start to be addressed when it is challenged through research based evidence, the raising of public awareness and the ability of health care practice to free itself from bias. Further research and education will play a pivotal role in achieving this. This paper can be seen as a 'geological' report showing 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 experience prejudice with regard to their ED.

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