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Growing older with post traumatic stress disorder

Curran, B and Collier, EH

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Bernard Curran
C/O E. Collier

E. Collier
BSc. MSc. RMN PGCE PhD
Lecturer in Mental Health
School of Nursing, Midwifery, Social Work & Social Sciences
University of Salford
Frederick Rd Campus
Salford
M6 6PU
0161 295 2729
e.collier@salford.ac.uk

Title

Growing Older with Post Traumatic Stress Disorder

Short title

Growing Older with PTSD

Abstract

Ageing with mental illness is a neglected area of research and policy. People who grow older to later life with on-going mental health problems may not have their needs well understood. This understanding is important if mental health services are to ensure direct or indirect age discrimination is avoided. This paper discusses the issues of ageing with mental illness over a prolonged period of time with a focus on one person's story, Bernard, of ageing with post-traumatic stress disorder in the UK. Implications for practice are discussed in the context of life course, recovery, self-help and preventing suicide. The narrative illustrates how time, memory and meaning interweave and how ageing with mental illness become part of a person's ongoing identity.

Key words Experience, long term, mental illness, older people, Post Traumatic Stress Disorder

Summary

What is known

- 1** The needs of older people with long term mental illness are not very well addressed in policy and research
- 2** Older people are not a homogenous group and people ageing with long term mental illness have potentially unique or specific needs.

What this paper adds

- 1** A unique example of the idiosyncratic and contextual nature of individual strengths and the abilities in managing personal recovery when experiencing long term mental illness
- 2** Emotional exhaustion experienced after long term mental health compromises the ability to manage feelings, potentially a special feature of life time mental ill health.

What are the implications for practice

- 1** Recognition that the hard work involved in successfully managing long term personal recovery may be important in preventing suicide in later life
- 2** The need to understand a person's life story to make sense of their experience of mental illness and to recognise long term mental illness to later life as part of a persons established identity
- 3** The importance of appreciating the place of early memories for understanding older person's mental health in their present.

Introduction

People of 'working age' (those under the age of 65) with long term mental ill health have been recognised as a neglected majority of people in the UK with mental health problems (Rethink, 2004; Sainsbury Centre for Mental Health, 2005). If this is the case then it can be argued that older people (over the age of 65 years) are even more neglected and remain invisible (McKay, 2010): a neglected minority within the neglected majority, with little representation or opportunity to have their voice heard (Collier & Edwards, 2013). Older people are often categorised into one 'group', an 'absurd but inescapable' practice (Latimer, 1997: 143) as age cut offs have no particular meaning (Department of Work and Pensions, 2005; Royal College of Psychiatrists, 2009). Life course perspectives help avoid age distinctions and instead focus on historical and geographical location, social ties to others, human agency and timing of events and roles (Elder & Giele, 2009). This may be

particularly important when considering the complex variety of cultural perspectives round the world and the myriad ways in which individuals develop.

There is a qualitative difference between being an older person with mental health problems, and being someone with mental health problems that happens to be older, having had long term mental ill health from an early age and grown older. The latter have been referred to as ‘graduates’, graduating from early to later life services at age 65 (Kalim et al., 2005). Ageing with mental health problems to older age is a neglected area of research and policy particularly from an experiential rather than a medical perspective. Listening and hearing patient stories has been surprisingly limited in the academic literature (Casey & Long, 2003; Hawkins & Lindsay, 2006; Jensen & Wadkins, 2007).

Bernard, the first author of this paper and whose story is told here died in February 2015, just after the paper was completed. He was a self-sufficient man who had lived alone in a council bungalow since his wife’s death in the early 1990s. He had accessed community mental health services at different times over the years, but in latter years had sought support only from his GP. His goal in life was ‘to make people smile’ and this is what he went out and tried to do every day, volunteering in various community projects. His mission in life had become telling as many people as possible about his experience in order that they could understand mental illness. The tense of the latter parts of his story have been altered to past tense. In this paper, Bernard’s story will be presented followed by a discussion of the implications for practice in relation to life course perspectives, contemporary recovery and self-help, and preventing suicide in older people.

Aim

This paper aims to explore issues relating to later life and ageing with mental illness focused on the story of Bernard (who was 84 years of age at the time of writing) who lived with a diagnosis of post-traumatic stress disorder (PTSD) in northern England. He was not diagnosed with PTSD until around 1992 though he started experiencing mental health problems around 1953 at the age of 23.

Methods

The paper is co-authored by Bernard and the researcher he originally told his story to as a participant in a biographical research study exploring mental ill health through the life course. He wanted to reveal his identity and publish his story for the benefit of others. In the original research study, his story was co-constructed by first being asked to complete curriculum vitae (CV) of his life, a tool that focuses on achievements. The CV informed two personalised interviews that were reconfigured to create a biography that illustrated a coherent individual trajectory, presented within a temporally organised whole that followed a chronology from birth to the present (Polkinghorne, 1995; Poirier & Ayres, 1997; Wengraf, 2001; Gibbs, 2002). An edited version of this is presented here for the purposes of publication as a service user narrative: the words used are his words. He wanted people to understand that this was not an 'illness' story, it was his life story.

Ethics

Posthumous publications of personal narratives are not necessarily straightforward (Weiss Roberts & Dyer, 2004) and there is very little guidance for posthumous publication in the context of service user narratives. Most literature available concerns disclosure of medical information after death, or doing research on dead subjects. However, Wilkinson (2002) says

‘...posthumous wishes of subjects can matter in their own right after their death’ (p32), and this is the principle I have drawn on in making decisions about this paper.

Bernard originally consented to the research (in 2006) on the usual basis of confidentiality and anonymity, and this included consent for quotes to be used in publication. However, he decided to identify himself when he agreed to tell his story to student nurses in the classroom. He did this many times from 2007 up to the end of 2014 as it was very important to him to help them learn about mental ill health, particularly PTSD. I raised the possibility of him publishing his story for a wider audience, and he was very keen to do this. I (second author) wrote the draft paper and gave it to Bernard for comment. He was keen for me to go ahead and submit it. Unfortunately he died unexpectedly 2 weeks after this meeting. His family were aware of his involvement with the university and how important it was to him to tell his story as widely as possible. They were also aware that his story had been sent to an international journal for publication and they are proud of his achievements.

Bernard’s story

Bernard was born in 1930, one of seven children who lived in impoverished circumstances in inner city Salford. His Mum, a *‘determined’* woman and a *‘wonderful character’* who had been born in the workhouse, did her best for them. He did not know who his dad was; it was one of four possibilities. They lived in a *‘cockroach ridden’* environment with little to eat, no shoes and *‘arses hanging out of our pants’*. His *‘mam’* fought to keep her family together, *‘she worked bloody hard’*. They survived by *‘half inching’* apples and bottles of milk, and chopping wood to earn money. They;

‘...picked over the tips...picking up coke in whatever weather, to have a fire...loads of blinking wood from the bomb sites on the fires just to keep warm...we had no electric,

we couldn't afford it. We had candles and thing like that. I suppose it made me a better man. I don't know'.

Bernard was the 'runt' of the family and had 'every disease going': diphtheria, pneumonia and scarlet fever, but the most serious was peritonitis at age 10. As there was 'no national health service' they walked all around Manchester from one hospital to another because they 'couldn't afford buses', and each hospital said 'sorry full beds'. Bernard was in severe pain and there was only one place left to try; the private Jewish hospital. They took him in and he was 'lucky to survive'.

Two years later, during the second world war in 1942, Bernard was evacuated to a family in the country. He ran away, took a jacket and boots from his home, 'lied about his age' and joined the Merchant Navy. He was 12 years old. He sailed with them around the world for three years with no military protection and they often picked up dead bodies from the sea.

His mum had thought that he was dead but he returned at age 15 and found work as a tailor. At age 17 he joined the army and spent much of the time in the Middle East, where he got 'his comeuppance'. His patrol ended up fighting in Tripoli, 'street fighting' that they were not used to. They had to 'watch their backs' all the time, they could 'never relax', always expecting a 'knife in the back'. They had to go through mine fields that were supposed to have been cleared by the 'sappers', but all too often a mine had been missed. On one occasion one of the 'lads' walking in front of Bernard stepped on a mine and was blown up;

'We thought it was clear...So we went in we was in single file orders...I was in the bleeding back, tail-end Charlie as usual, and I was walking backwards covering...but what happened was the radio man...It wasn't like they are now...you know, transistors. It was very big, and he used to have to hook it on his back and it was very heavy with a big aerial and...he must have stepped off the line and I can only think it was the weight, you know of his radio, and he put his foot on this bloody mine and went. So all I remember after that was this flash. The one in front, he copped out... got it all in the back. The one behind him, he copped out, but he saved the others

because he took the full doings, but I...got hit because somehow or other it missed this other guy and hit me, you know, and all I remember after that was being taken to the British Military Hospital in Malta'.

When Bernard returned to the UK as an injured soldier he was not allowed off the boat until nightfall; *'the public did not see the lads carried off. It was dead of night when the SS Empire Pride docked at Liverpool, so Hay Ho back to blighty, to what?'*

After a period of unemployment Bernard joined the Territorial Army. By this time he had met his future wife and one day she came to him *'very upset'* because she was pregnant. Bernard was *'over the moon'* and marriage followed *'hurriedly'* in 1953. It was not long after his marriage, when his daughter was a baby and he was in his early twenties, that Bernard started feeling particularly frightened, but he did not know why. He began to experience *'sweats...shaking all over and I just couldn't grip it'*, but it was when he left the Territorial Army a few years later that he was *'not the same man in any way shape or form'*. The doctor said it was *'nerves'* and prescribed some tablets. Around this time Bernard and his family had the opportunity to take a *'ten pound passage'* to Australia (a post war assisted migration package scheme established by the Australian Government). His wife really wanted to go, but he just *'couldn't do it'*. He was frightened, he could not focus and he wondered *'what the hell's happening to me?'*

He started a job as a driver of a *'bin wagon'* with the council but he continued to experience *'dizziness', 'sweats', 'fear of going out'* and *'nightmares'*. He could not walk down the street without encouragement from his wife urging him on *'get to the corner this time'*. He would *'brush against the wall'* so he was *'further away from the traffic...cos I kept getting fears...going across the road and getting hit by a bus...I was frightened to death'*.

Bernard feared that he would 'hurt' someone, 'especially women'. He thought that he was a 'lunatic'. He was fearful of his children, about what he might do to them, and said his feelings were 'not the way a man or a woman should think'. He could not tell anyone, not even his wife about his thoughts and feelings because he knew that if he admitted to being a 'lunatic' he would 'be in the bloody nuthouse...I'd be gone and my wife and my kids, who'd look after them...I had no way to make sense of it, all I thought of was 'Bernard, you're a lunatic' ...For some reason or another me brain had gone and...as a lunatic I should be in a bloody padded cell in wherever'. His fears prevented him from enjoying ordinary family life; trips to the park, dances, family holidays. He would sit gripping the side of his deck chair 'frightened of everybody and everything...it was hard work'.

He always ensured that his hands were full so that they 'couldn't be used for anything bad'. He would 'get two morning papers instead of one and roll them up, one in that hand and one in the other so me hand was doing something instead of, you know, hurting anybody or whatever because I was holding something...it did help me'. His fear of going 'mad' ensured he never had a day off work. He was seen as 'easy going', and he would get up early and arrive there at 5.30am because it was 'very quiet'. The job, driving a bin wagon meant that his hands were kept on the steering wheel. Being at work 'rested' his 'mind' as he could concentrate on the job and not think about his fears. However, once Bernard found himself in the 'furnace room' fighting the compulsion to put his hands on a hot plate because 'if they were burned off' he couldn't 'hurt anyone with them'.

Whilst working on the bin wagon on a rainy day around 1959 he found a book in the rubbish;

'...something to do with peace from nervous suffering by Claire Weekes...I took it home and I read it...parts in the book said 'This is what my patients said they do.' So I looked at one that said 'I was afraid of this, afraid of that and I wouldn't do this,' and I thought these are beginning to fit into my fears...and it made me feel a bit better

knowing that someone out there in the world had got the same...something similar to mine. So I used to read it and that used to buoy me up'.

In the early 1990s a health visitor visiting his wife noticed Bernard's 'strange' behaviour, his 'nervous twitch', and his military photos on the side. She asked him 'how long have you been like that?' and whether anything happened to him while he was in the forces. He told her about his 'fractured skull and shrapnel. She said 'Nothing else?' I said 'Never mind nothing else. It was bleeding bad enough'. Her intervention resulted in an assessment with military doctors which eventually led to a diagnosis of PTSD and the award of a pension. Bernard was not able to share this with his wife however, as she died two weeks before he received the letter in 1992. The impact of her death led Bernard to request admission to a mental health unit which he did not find helpful and stayed only for a short time. Not long after this he tried to kill himself as there was 'nothing left' though he was worried about upsetting his daughter. The organisation Combat Stress became very helpful as he started to mix with others who had similar problems and Bernard felt he 'was no longer alone', forty years after the onset of his first experiences. After a while he stopped going though as he found it too structured and he wanted to leave military style life behind.

Bernard continued to struggle in later life with his feelings at times such as on holiday;

'...we went up to Hitler's lair in the mountains, I couldn't do it. I stayed in the middle of this building up there – and it was a fantastic building right up in the mountain, a sheer mountain. I stayed stock still there. I could not move or do anything because I was frightened to death I might suddenly jump over'.

He felt 'better in myself than I did before' and having a name for what was wrong was helpful; 'I knew then what was causing all this...It's all an effort but not as much as years ago when I knew nothing'.

He was exhausted at the energy it took to get through each day. He tried to help people ‘...put a smile on people’s faces’. This helped him manage his own problems even though he still had ‘blue days’. He was lonely but was hopeful that he would meet a female companion, someone who could understand. He had friends but as he reflected:

‘...they go home and the door closes. That’s the way it is though. I accept it and it’s hard, but what else is there to do...I have that alopecic (cannot be bothered) feeling now...if your numbers up your numbers up’.

Implications for practice

The concepts of life course, recovery and self-help will provide a framework for discussing the implications for practice and in addition, suicide prevention in older people will be discussed.

Life course

Bernard’s story provides a unique example of the significance of historical and geographical location, social ties, agency, timing of events and roles as theorised in life course theory (Elder & Giele, 2009) in thinking about ageing with mental illness. The story demonstrates a longitudinal picture not always appreciated in cross sectional research studies or indeed in mental health care where, with the focus on the here and now, the meaning that past experiences have for individuals is not always valued (Russell, 2007). This mirrors Bernard’s experience as when he tried to tell his story to a psychiatrist he was told ‘*I’m not interested in your past...all I’m interested in is your future*’. Although the narrative is retrospective it offers insights into his thoughts and feelings and how he interacted and interpreted his experiences within the socio-cultural context of the times he had lived through. As PTSD was not recognised in diagnostic manuals until 1980 (APA, 1980) so not available for Bernard, his framework for interpreting his experience was limited to the cultural norms of the time where ‘being a lunatic’ and its treatments instilled fear and stigma.

A Life course perspective requires us to notice the potential relevance of the past in later life mental health. For example, a comprehensive assessment would usefully identify that Bernard was aged 9-13 during World War two, where his development would be affected by nutritional deprivation, family separation and social upheaval; that he was 18 before he had access to a free national health service, as well as recognising his resilience borne from his early life experience and relationship with his mum. We can only surmise the effect of transatlantic voyages often under gunfire on an unsupported 12 year old boy in 1942, though Bernard recalled these memories with humour and pride rather than distress. Bernard never made any connections himself between his military experiences and his mental ill health, and his GP blamed him (in Bernard's words) for not alerting him to his early experiences. This perhaps illustrates the need for professionals to be mindful of making these potential connections in mental health assessments. Early life experiences have been shown to have a significant link with later life mental health (Kraaij & De Wilde, 2001; Kraaij et al. 2002).

In diagnostic terms, Bernard was unusual in that he was one of the 'small proportion' of people for whom PTSD followed a 'chronic course over many years' (World Health Organisation (WHO), 2010). The needs of older people with long term PTSD are not well understood and they may not respond to treatments developed with younger people; they also face added vulnerability in relation to biological ageing and physical health needs (Black & Collier, 2014). This lack of understanding is also reflected in other areas of practice for example how recovery values have informed mental health care for older people.

Recovery

Recovery principles are core values at the heart of mental health nursing (Department of health (DH), 2006). However, Daley et al. (2013) (in the only research paper focused on recovery in older people), attempted to evaluate how far recovery frameworks which have

been developed with younger populations were relevant for older people. They found that there three distinct differences: the significance of an established and enduring sense of identity (as oppose to adapting to a new identity), coping strategies which provide continuity and reinforce identity and the associated impact of physical illness (Daley et al., 2013). Bernard perhaps illustrates this enduring sense of identity, where rather than classifying his experience as an illness, it had become who he was; it was his life.

Recovery values require nurses to have positive expectations, engender hope and work towards personally defined goals (Buchanan-Barker, 2009). For Bernard, because of his drive to provide for his family, he was able to navigate a way of living with and managing his experiences, therefore making his job sustainable. Work is what kept him going and it was essential in managing his mental ill health;

‘...while you’re working your mind is giving itself a rest because you’re working. You’re not thinking most of the time, you’re working, so while you’re working your mind and your brain is resting. Your brain is centred on the job and not thinking of fears. That’s why it’s the best thing to work with depression and that’s what I found out. That’s why I threw everything in me job, everything’.

Self-help and preventing suicide

The dynamic nature of suicide risk is illustrated in Bernard’s story and is suggestive of the abilities people have to manage their own recovery (Sullivan, 1994; Marin et al., 2005; Davidson et al., 2005). The book he found in the 1950s that ‘buoyed him up’ demonstrates the effectiveness of self-help literature in reducing a sense of isolation, congruent with contemporary recommendations (NICE, 2011). He also illustrates the sophisticated strategies that people can develop in their survival which are both idiosyncratic and situational. For Bernard walking down the street with his ‘*back against the wall*’, keeping his hands full with newspapers and his steering wheel at work, were strategies born out of necessity that enabled longer term survival and success. This was driven by his key goal: to stay out of the mental

asylum so that he could care for his wife and kids. Focusing on the anticipated transition in his children's lives helped him manage his suicidal feelings;

'...what I kept saying to myself was as soon as my kids started work looking after themselves...I couldn't give a toss what happened to me. I was satisfied to keep going until they started work'.

This became a goal that shifted through time, as although his children have grown up and become independent, his role as a father and protector remained his motivation for staying alive;

'I used other excuses then. Me daughter had kids, 'I must keep going for their kids'...when I'm down suicide grips me but we got to go on it would upset my daughter'.

Bernard statistically belonged to a high risk group for suicide, being widowed, male and over the age of 75 with both physical and mental health problems (Fung and Chan 2011; DH, 2012; WHO, 2014). However, his resilience and personal strategies appear to have had a protective function over a long period, until the added distress of the death of his wife. This illustrates a little recognised feature of recovery as an exhausting long term process of hard work (Sholtis, 2002; Deegan, 2003; Morisey, 2003; Weingarten 2005). This was evident for Bernard where his ability to manage these feelings was compromised by emotional exhaustion after more than 50 years of effort, which can perhaps be considered a special feature of life time mental ill health in later life (Collier, 2012). As Bernard's story implies, PTSD is experienced as a syndrome that encompasses a range of mental health problems including depression. Guidance from the Royal College of Psychiatrists (2010) indicates that to prevent suicide in older people there needs to be recognition by services that they should:

- actively treat depression in later life
 - have a low threshold for referral to specialist services for older people
 - end the discrimination in their access to services in general
 - not underestimate the seriousness of self-harm and suicidal behaviour in later life.
- (p3).

The recognition of limited evidence focused on older people with ongoing PTSD, and more specific interventions for PTSD are discussed in Black and Collier (2014).

Conclusion

This paper highlights the emotionally exhausting nature of long term mental ill health to older age. The emotional cost Bernard saw as payment for maintaining stability for his family, and this price he felt was important to acknowledge as otherwise *'it would all have been for nothing'*. His story indicates that life course approaches to later life mental health are important if we are to provide sensitive and meaningful care. It can help challenge artificial age distinctions and instead encourage an awareness of the importance of life history in clinical interviews for people of different ages (Kraaij & De Wilde, 2001).

Bernard viewed the opportunity to tell his story as a turning point in his life, and he often told me that, *'it saved my life'*. It introduced him to a new opportunity to contribute to nurse education, telling his story regularly to cohorts of student nurses. And in the end, despite his adversity, he said:

'...I wouldn't swap me experience because it's made me what I am now...It's my life. It's fate, it's what happened. There's no going back to it'.

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