A Tale of Two Stories: A Narrative of Bulimia in a Research Study of Anorexia, and the Dilemmas of a Novice Researcher

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ABSTRACT
The purpose of this paper is two-fold: Firstly, it reports on one man’s experience of bulimia. After being interviewed it became evident that he did not meet the inclusion criteria for the study, which was focussed on anorexia in men. Secondly, the paper explores the implications for a novice researcher of including someone in a study who does not meet the inclusion criteria. The researcher’s story reflects upon the implications of self-doubt when embarking upon sensitive research, and the morality of holding onto a rogue participant’s story. It offers others an opportunity to consider and learn from this experience.

Introduction
It has been suggested that whilst academia ignores men with eating disorders (EDs) (King, 2019; Lyons et al., 2019), in-patient admissions of males in the U.K. with such disorders have increased dramatically since 2000. Knowles (2011) suggested a 66% rise, while more recently Marsh (2017) reported a rise of 70% in men admitted to hospital for EDs. However, regardless of the increase, in the UK these figures remain in the low hundreds (National Health Service (N.H.S) Digital, 2020), and may explain the dearth of male specific academic research published since 2000 (Lyons et al., 2019). In addition, these statistics only show the actual numbers of men admitted into specialist in-patient treatment units, and do not take account of males receiving outpatient treatment, or those who have an ED, but who remain outside of the healthcare system.

Section 1 –Steven's background story
Childhood
Steven specified that he has experienced two families, the one he was born into and the one which he chose through his marriage. His comment that “you can pick your friends but not your family” summarised his thoughts about his relationships with his parents and sibling.
Steven described growing up in a suburban area as "idyllic in one sense, but horrible in others." He used the terms 'fractured', 'difficult' and 'uncomfortable being around them all' to describe his experience of family relationships during childhood. When asked to describe his family background, Steven's tone of voice was flat. He said of his natural father,

Dad is long gone, dead. If it's anything he used to knock the s*** out of my mum, bit of a vile man, run off with loads of women, kids, just a bit of a rogue really...Drink was always prevalent in the house with my dad. Dad was in pubs, so I was always in the pub, alcohol has always been an issue.

Violence was also a feature of his upbringing; whilst his father struck his mother, Steven reported being struck himself. At some point during his childhood his father died, and his mother remarried, but the violence did not stop; “I had a step-dad knocking me about.” When describing his father and stepfather Steven said; “there was quite a lot of alcohol and violence on my dad's and step-dad's part.”

Steven indicated that as a child he felt ‘fat’ and ‘constantly dieted’. In trying to combat weight gain he would go to an area of the garden where he could not be seen by his family and exercise by walking up and down repeatedly for long periods of time. Steven commented that when growing up his friends were ‘good’, although when speaking of his own behaviours, he said;

I was a bit of a c***, I was always doing this and that, crazy stuff. So yes, I was quite popular I was always a laugh with all these dares. Yes, I was popular as a kid, I wasn’t hiding away.

It was not clear if his friends took part in the same ‘crazy’ behaviour or if his popularity was related to him being perceived as the joker. Steven went on to say; “I did really stupid gormless things just for the dare.” However, Steven did state that he had indulged in taking drugs and drinking, and spoke of being a regular customer at a night club ‘notorious for its music and ecstasy culture’.

In his late-teens/early-twenties Steven started to engage in what was later diagnosed as Non-Purge Bulimia. Steven stated that he only recognised his bulimic behaviours when he started living with friends. Steven also stated that he had previously used self-harm, cutting himself and overdosing on painkillers. Around the age of twenty, Steven was diagnosed with bi-polar depression.

Section 2 - Steven in his early 40s

At the time of interview Steven reported that he was short in stature, overweight, and had a high body mass index (BMI). He was married with a young child, and worked part-time while his wife, a professional, was the main income earner within his family.

Bulimic behaviour

Steven's eating disordered behaviour had escalated since his original diagnosis of non-purging bulimia. At interview he spoke of how he was restricting food, exercising to try and burn calories, and had recently started purging through vomiting. A normal day in Steven's life would consist of trying to restrict his food and calorific intake as much as possible. However, he would lose control and binge at night, eating at least 1,000 calories. He also reported problems with an inability to stop drinking when he started his night binges. This led to excessive exercising on the following day to burn calories and lose weight. Steven said;

I am only happy if I wake up and I feel dizzy. If I am dizzy I know I haven't had the calories and know I've lost weight, so I associate being light headed with being thin and happier.

He spoke candidly about his binge eating behaviour, citing the binge he had the night before his interview, which included a punnet of grapes, three loaves of bread, two tins of soup and cheese. After disclosing this, Steven added; “that's not a normal thing to do at 2 o'clock in the morning.” This lack of control around food when engaging in a binge was described by Steven as;

It's weird, like you can't see what's going on around you, you are so focused like if someone walked in a room when I was going through 10 packs of crisps or a box of chocolates or with my hands getting a portion of chips out of the bin, (out of my own bin, I would never do that on the street, can I just stress that?) I wouldn't be able to see the person walking in. I would be that focussed on that, it's almost like you've got no control, I can't explain it. Tunnel vision, you are just focussed on that.

Tunnel vision is considered a natural human tendency that has particularly pernicious effects, and is often the result of institutional and/or cultural pressures (Findley, 2012). When Steven started binging, he felt he could not stop until he had cleared the food cupboards at his home. He had also resorted to spoiling food with washing up liquid in-order to not be able to eat it. When living alone he was able to control his behaviour by not restocking cupboards. However, in his family setting (wife and child) there was much more food in the house and his behaviour put pressure on the family's resources. Steven stated that he had considered putting locks on the cupboards, but decided against this, possibly because it was an admission of a loss of control, often a problem for those with bulimia (Goossens et al., 2009).

Purging

Additional to his binge and exercise behaviour, Steven reported that he had started to purge calories through vomiting. This escalation in his behaviour had been something he had tried to do unsuccessfully on previous occasions. He said;

Well it's something that I've wanted to do, but I can't do it because it's so unpleasant that I've never actually been able to perfect how to do it properly, it's not through not wanting to, I can't do it.

His use of the word 'perfect' was concerning in terms of its descriptiveness and the matter of fact nature in which he said it; he could have been talking about anything rather than forcing himself to be sick. Steven's next comments were
also concerning, as they could potentially have major implications for his future health and well-being; he reported a breakthrough in perfecting his vomiting technique, “I managed to do it the other week which I’m not proud of obviously.” The use of the word ‘managed’, within this context, suggested an internal battle to overcome the unnatural behaviour of inducing vomiting. Steven talks of ‘knowing what to do now’, indicating that he had found a technique to make himself sick, enabling him to ‘manage’ the unpleasantness of such action. Finding a way to vomit created ambiguity for Steven; it allowed him to purge much more easily and effectively than exercise, but he also recognised how dangerous it could be; “However, I’m quite worried that I will end up going down that route.”

Seeking help

Although Steven had previously received treatment for depression and self-harm, approximately five years before being interviewed he sought help from his GP for his eating behaviours which he believed he had experienced since being around fifteen years of age, and was referred for therapy. Steven said he found the therapy helpful, but dropped out at an unspecified point. Steven suggested this was because he could not get childcare, and he did not want to tell his employer or miss work. Regardless of his intention, Steven had not restarted therapy within the past five years. He stated that during this time period no one from the health service had asked him why he had dropped out of therapy. However, it must be stated that during this period of his life he moved home on more than one occasion and changed GP practices and services.

Steven believed the GP he sought help from after moving was not interested in his bulimia, but focussed on medication and his previous depressive episodes. Steven was asked why he had not tried to get help for his bulimia, but he believed that he had. However, he also believed he had been ‘fobbed off’ with medication or online Cognitive Behaviour Therapy (CBT). His experiences of being treated over the previous years for depression made him sceptical of treatment in general. Although he did recognise the need to re-engage with treatment Steven never referred to this within the context of being part of a family. Living with mental health problems can be burdensome, not only on the person experiencing them, but also for their family (Wilkinson & McAndrew, 2008). His lack of acknowledgement of how his not re-engaging with treatment might impact his family may indicate self-absorption with his bulimia, or it could be a way of distancing his bulimia from his family by keeping them out of the conversation as much as possible.

Employment

Steven worked part-time within the health and social care sector; with one of his roles being to prepare food for the people in his care. Steven had never told any of his employers about his bulimia, as he believed this would hinder him getting a job and/or his employment might be terminated. His fear may have some grounds; the UK mental health charity Mind suggested that 15% of people had experienced disciplinary action, demotion or dismissal after disclosing a mental illness. Worryingly Mind also stated this was an increase from similar research carried out in 2016 which indicated 9% of people had experienced similar actions (Mind, 2017). During the interview Steven briefly raised the question of his capability being a potential problem with his employer. Steven stated;

I can’t have these issues myself and let people know about it, you know. How can I do my job properly when I am potentially in the same position as them [those he is providing care for]?

However, he himself felt that because of his experience he was more empathetic than others potentially could be.
There is evidence to support Steven's belief. Wright and O'Toole (2006) suggested experiencing an eating disorder enhanced professionals' client work through improved empathy and understanding. Despite thinking his capability to work was not affected, Steven did state that when he felt unable to control himself around food, he would absent himself from work on that day.

I know I am going to binge I will phone in sick because I know I have to prepare food for [x number] of people. That's a really difficult thing to do when you've got an eating disorder.

While this could be considered admirable on Steven's part, knowing himself enough to admit he is not fit to work, it is likely to cause a problem for his employer who, at short notice, would have to find someone to cover his work or compromise the safety/service of the people he cares for. It was not ascertained if Steven worked within statutory or non-statutory services, but recent NHS Employers have published initiatives on their website encouraging managers to support employees who experience mental health issues. For example, How managers can support workplace mental well-being and mental health in the workplace (NHS, 2019) stipulated, "where possible reasonable adjustments should be made", but this is difficult when an employee does not admit to a current or pre-existing condition.

Steven also cited a further barrier to him telling his employer about his bulimia. This related to his belief that he would lose face/respect from his work colleagues, as he had experience of them being disparaging towards people with mental health problems.

Steven's comment is concerning, however indiscriminate gossip in the health and social sector is known to have a number of negative implications for both staff and patients, and could be a sign of burnout and disassociation on the part of staff with patients (Georganta et al., 2014).

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Steven's perceptions of male bulimia awareness and stigma

After twenty years of mental health problems, Steven appeared fatalistic in his view of portrayals of EDs and lacked belief in them improving. He believed representations of adult men experiencing EDs were tokenistic. Steven stated: “You never hear it of blokes my age, I'm [exact age] soon, and you never hear it happens. I am sure they just chuck us in as a token gesture, for equality and diversity.”

Steven went on to suggest representations were most likely to be gay men, this being in keeping with wider stereotyping of men experiencing EDs, but having the potential to be harmful to heterosexual males (Jones & Morgan, 2010; The UK National Centre for Eating Disorders, 2019; Muhlheim, 2020). Steven believed that the only way to increase awareness about male EDs was for men to come forward and share their experiences, but felt that in certain demographics of the male population this was unlikely to happen, primarily due to masculinity and the stereotypes of male EDs clashing. Steven felt he was able to come forward with his story because he was different to other heterosexual men, he was emasculated and ‘not a proper’ male, even though he was married with a child. He felt people thought of him as gay, due to a dislike of football and DIY, his female friends, his lack of aggressiveness and his dislike of stereotypical male behaviour on nights out. Steven said “I don't feel like a proper grown-up man, like my dad was, or my granddad was, or my neighbour is. I just feel like a man-child really.”

The researcher's story

Accepting a man with bulimia for a study focussing on anorexia

Steven was keen to participate in my narrative study of men's lived experiences of anorexia. He felt that some of his behaviours (food restriction and excessive exercise), were similar to those of anorexia. At this point I must acknowledge my own interest in the topic being borne out of my personal experience of an ED. Similar to Steven I was originally misdiagnosed with bulimia, but this was later changed to one of anorexia. Initially, prior to starting the interview Steven described symptoms akin to those I had experienced and his belief he had misdiagnosed. For these reasons I persuaded myself that he might also have anorexia rather than bulimia. With hindsight this was defensive on my part regarding recruitment to the study and problematic. While Wright and O’Toole (2006) suggest experiencing an ED enhances empathy and understanding, the shared commonality could lead to blurred boundaries for the researcher and the participant (Moodley, 2001).

However, even though it was explained to Steven that he may not fit the research parameters, he was keen to share his story. This presented a dilemma for the myself as a novice researcher as, being cognisant of Steven's potential vulnerability, I did not want to cause him additional distress. The benefits of participating in research are often overshadowed by a preoccupation with risks associated with working with those considered vulnerable (Warne & McAndrew, 2010). Paradoxically, a focus on protecting participants from harm and cushioning vulnerable people has been construed as a violation of the important ethical principles of autonomy and justice, whereby people might be withdrawn from research studies, not included, or their viewpoints rendered irrelevant (Rogers, 2004). Rogers's (2004) position regarding protecting and cushioning vulnerable people to some degree reinforces my personal perspective. Being a novice researcher, I was fearful of rejecting Steven; I did not want him to feel how I had felt when I had volunteered to participate in research studies and been rejected. In light of this, interviewing Steven for the study could be considered an emotional decision, rather than once based on more objective inclusion criteria. The dilemma of Steven being a vulnerable
person raised questions which formed their own narrative for myself and my supervisors, and are appropriate to share with the wider research community for discussion and reflection.

Steven was interviewed and his story was analysed in the same way as the other study participants (for more details of the primary research see (Lyons, 2018)). During interview it became clear that his binges were bulimic in terms of calorie consumption and him having a high BMI, neither of which would fit the medical classification of anorexia. However, regarding his weight, this does not preclude Steven from associating his behaviours with anorexia, as research has shown that men with anorexia tend to be overweight at the beginning of their illness (Cooperman, 2000; Strober et al., 2001; Fernández-Aranda et al., 2004; Freeman, 2005, Raevuori et al., 2009; Guéguen et al., 2012). As a means of overcoming the problem of having a participant that did not meet the inclusion criteria, as a novice researcher I widened the scope of the research to use Steven’s, and other potential narratives of men who experienced bulimia, to compare and contrast their experiences with those of men who were diagnosed with anorexia. This soon became problematic as Steven was the only man diagnosed with bulimia who came forward so using his story to compare and contrast with stories of anorexia was impossible when writing up the final thesis. Even with qualitative research not being generalisable, only using a single story as a point of reference was not good academic practice.

Reflections on changing a research study to accommodate a single respondent

Although the focus of the study was men’s experiences of living with anorexia, I believed that men who experienced bulimia might come forward. For this reason, I thought I needed to be flexible and willing to changing the focus of the study. With hindsight this was a superficial decision, as I had not given thought to the wider implications of changing the study focus. As a man who has experienced anorexia, at the start of my PhD journey my personal focus was on getting answers to my own personal questions, and to try, in a small way, to help other men not to have to face the challenges I had encountered. In many respects, and as Moodley (2001) suggests, I could have been undertaking this research to search for a missing link, correlation, new knowledge and/or increased understanding of EDs. Consciously and from my own personal experiences, I did not want to “shut the door” in anyone’s face and this may have contributed to my agreeing to interview Steven.

The UK ED charity, Beat, had been approached to help recruit participants, as they have an internet presence and hold a small database of people interested in becoming research participants. They had not initially advertised the study via their social media platforms, but had distributed information relating to the study to their list of those interested in being research participants. Steven was one of two people who responded to this call, and as a novice researcher and the passing of time, I was beginning to worry that I would not recruit enough participants to my study to create an interesting, valuable, and meaningful piece of work; hence my keenness to interview Steven. At this point I also believed that at least one more man experiencing bulimia would volunteer to participate in the study which would enable some form of comparison of experiences of those with bulimia and anorexia.

This situation was anxiety provoking and discussions took place with my supervisors as to whether the study could be changed to accommodate Steven’s story, a man who experienced bulimia rather than anorexia. I believed that telling Steven’s story was the least I could do for him, as he had taken time to help me, a complete stranger, with my work. After agreeing this could be feasible if more men came forward who had experienced bulimia, a total of seven interviews took place, but all with men who had experienced anorexia (see Lyons et al., 2019 for details of the main study).

From an academic stance, although the original study had intended to focus on anorexia, the background reading of the topic had indicated a lack of research into bulimia generally, and specifically in comparison to anorexia. The lack of research was interesting given bulimia is much more prevalent as an ED than anorexia (Hay et al., 2015; Frey, 2020). However, inpatient admissions were nearly 20 times greater for anorexia than bulimia (N.H.S Digital, 2020). Background reading and recognising the gap in academic literature, coupled with my anxiety over recruiting participants, may have influenced my enthusiasm to interview a man who had experience of bulimia, regardless of my study focussing on men experiencing anorexia. For his own reasons Steven wanted to share his story in an academic setting. It was clear that even if Steven’s story could not be used for its original intended purpose, his standalone narrative could be shared with a wider audience via publication in an academic journal, demonstrating the lived experiences of a man experiencing bulimia in 21st century Britain.

From a moral perspective, Steven had taken the trouble to engage with the study and wanted to take part even when the parameters had been explained. Perhaps due to my own experience of anorexia and the difficulties I encountered getting a correct diagnosis and appropriate treatment, when Steven shared, via email, his own doubts about his bulimia diagnosis and stating why he should take part in the study, I felt that I needed to give him an opportunity that I had not been offered. Also not knowing his background in terms of his mental health, I did not feel confident in refusing his participation, as I was concerned it might cause distress. Apart from the potential paternalistic nature of research with vulnerable people discussed above, Lakeman et al. (2013) suggest research involving participants’ telling their stories or exploring experience, can be beneficial particularly relating to the psychologically-important processes of feeling heard and consolidating memories. However, regardless of such benefits the blurring of boundaries needs to be acknowledged on the part of the researcher, especially where the latter has the desire to take on a helping role (Lalor et al., 2006), and/or be compensating to address gaps in their own previous experience.
During the interview Steven spoke of why he had stopped therapy and then, as if he was thinking allowed, spoke of his desire/need to re-engage within therapy. Choosing to participate in research can be unconsciously motivated by a desire for ‘healing’, with the therapeutic value of narrative inquiry emerging from its clarifying, constructing and cathartic functions (Warne & McAndrew, 2010). Steven appeared to use the opportunity as a participant as a cathartic experience and his involvement within the research may have itself been therapeutic. When using narrative research, it is important to acknowledge that the ‘storying’ of experience offers opportunity to make sense of a person's lived experience. The retelling and reliving of the story through a process of personal reflection can itself be therapeutic (Warne & McAndrew, 2010).

**Holding onto Steven's story**

After all the interviews had been concluded and Steven was still the only participant who experienced bulimia, I still wanted to include his story for a number of reasons, not least those described above. I felt I owed it too Steven to include his story. There were also valuable experiences that would provoke thought and discussion if shared. On a selfish note, I had already spent a significant amount of time transcribing and analysing his interview, discussing it with my supervisors and, despite their concerns, I therefore did not want to abandon it.

However, as the final thesis started to be pieced together it became clear that Steven's story was out of cinque with the work as a whole. From an academic viewpoint it would have created justifiable criticism as to why it was there, as it could not be used as a comparison and appeared as something bolted on to the thesis as an afterthought. Steven did not deserve this, nor did the other men who took part in the study. When writing up the final thesis doubts as to including Steven's story re-emerged. My decision to interview him and how it could be fitted into the thesis was discussed with my supervisors. Both challenged me as to how I would present Steven's story in a study focussing on men diagnosed with anorexia. Both explored my thoughts and feelings as to why I needed to include this story, and what its inclusion represented to me. While I found this conversation difficult and challenging, it did enable me to articulate the dilemmas I was facing as a novice researcher and also as a man who had experienced an ED. The discussions were a valuable tool to order my thoughts and processes needed to complete the research, Connolly and Reilly (2007) described a similar beneficial process.

As a team we discussed the merits of taking his story out and presenting it separately, and as such the decision to remove Steven's story and endeavour to publish it within a different context was made. As a novice researcher being able to fall back upon the experience of my supervisors who could clearly see the difficulties including the story would bring, it was a great relief to remove it. According to Roach et al. (2019) the supervisory relationship should be one of education, integrity, open communication, and constructive feedback, and it was these tenets that enabled me to submit a coherent thesis. The personal consequences of removing Steven's story were two-fold; at a practical level, potential problems over the word count of my thesis were removed, but more importantly, at a moral level, I was not having to fit his story into a frame that would not do justice to his experience. However, as time has progressed it has become a debt of honour, which I have allowed to impact my moving on with other research and has caused me to experience anxiety at times. Since completing my PhD, I believed that I had to try my best to have Steven's story published, as he generously gave me his time and shared his personal experiences with me for the greater good.

**From one novice to another**

I believe new researchers need to be clear in what the aims of their study are from both a personal and academic perspective. While it is important to be flexible, those undertaking research need to be cautious not to be so flexible that aims are abandoned in order to complete the task of producing an end product, albeit a PhD thesis and/or a research report.

Being honest with participants and ourselves, as researchers, is important. The participant has taken the time to say that they want to help; but because they have done this it does not mean a researcher has to accept them into their study. Not accepting them as a study participant, but offering a careful explanation as to why this is the case, may be far more helpful in the long term. From experience, I realise how difficult it is at times to share personal experiences, especially when those experiences carry a strong emotional component. I felt at the time of interview (and still do) that Steven found the interview beneficial. However, the reason for his binge the night before the interview could have been due to apprehension as to what he would share, or be asked to share.

Researchers must be aware that the drive for knowledge has to be tempered by the welfare of participants (World Medical Association, 2013) every step was taken to protect participants’ from gaining informed consent to signposting to medical services. However, researchers also need to be concerned about their own welfare and find ways to delinate self from research data, especially when exploring experiences in others that they have themselves been exposed to. When using narrative inquiry, and scrutinising each interview encounter, the unconscious processes present for both the participant and the researcher and the ensuing dynamic they create, can be explored through supervision akin to that of ‘clinical supervision.’ (Warne & McAndrew, 2010). In this instance using the supervisory team effectively and arriving at conclusions through exploration of thoughts, feelings, and discussion was vital (Warne & McAndrew, 2010; Roach et al., 2019).

Initially I did not want to engage in a study based around interviews, as I was unsure how hearing other people talking about behaviours similar to my own would affect me. It was at times very difficult, and whilst I did not embark on
another period of ED behaviours, the men's stories and experiences did make me feel depressed and down. This was partially due to hearing the participants' pain, but also to thinking about my behaviour and how it had affected people I loved and cared for, and how it had impacted my own life and career. However, undertaking the research also provided me with the motivation to get the work done. Whilst simplistic, cliched and perhaps egocentric, the thought of trying to help others similar experiences to the ones I and the participants experienced, enabled me to finish the research.

It was strange to listen to the men's stories about their experiences and at times it was very difficult. Perhaps the most dominant and, at the same time, conflicting emotions were those of anger and relief. Anger because I kept hearing experiences which were similar to my own, yet differentiated by health authorities and the services provided, and time. At times it felt as if men experiencing EDs did not matter, nothing had been learnt, and only lip service was being paid to this group of people. In contrast, it was a relief on a personal level to hear that experiences I felt embarrassed about were similar to those of other men, almost giving me a sense of I am not alone, I'm not abnormal. For me it is this last statement that makes the research so important, not only as a way of publicising the plight of men with EDs, but it made me stronger realising I had come through it and survived. It enabled me to achieve a postgraduate qualification.

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