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Case Title

Opening a door to a private world: Using auto/biographical methodology to explore health experiences

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Contributor Biographies

Dr Joanna Thurston is a Senior Lecturer in Sports Therapy at Bournemouth University. Following a 10 year career in Sports Injury Rehabilitation in which she worked with athletes from community to elite international level, Joanna started her academic career at the University of Bath in 2007, as a Teaching and Coaching Fellow and moved to

Bournemouth University in 2009. Here she established the Academy of Performance Coaching, was awarded a Learning and Teaching Fellowship for excellence in fusing education and professional practice and wrote and led the new BSc (Hons) Sports Therapy degree. Gaining her PhD in 2018, Joanna is now focusing her research interests on the experiences of non-traditional patients for conditions with a strong cultural stereotype, alongside continuing her work to raise awareness of premenopausal osteoporosis especially within the female athletic population.

Published Articles

Cooper K., Oliver, L., Podee. M., and Thurston, J. (2017). The personal stories of a methodological study group: An independent learning and support mechanism for post grads [online]. *Method Space.* Available from: www.methodspace.com/the-personal-stories-of-a-methodology-study-group/

Thurston, J., Oliver, L., Cooper, K., and Podee, M., (2018). From 'I' to 'We': A Collaborative Study Group Approach to Narrative Research. *The Qualitative Report. Under Review*

Abstract

This case presents an exploration of the challenges and implications of using the researcher-as-participant methodology of auto/biography, as a means of adding to the qualitative literature on patient health experiences. Based on doctoral work in which I explored my experience of living with premenopausal osteoporosis through reflective topical autobiography, this case highlights the decision-making process involved in choosing the most appropriate researcher-as-participant methodology to answer the research question. The application of the method and the ethical challenges associated with using such a personal process are explored and the unexpected issues that arose during the process are documented.

Learning Outcomes

By the end of this case, students should be able to:

- Articulate the differentiating features of three main researcher-as-participant methodologies.
- Appreciate the key ethical implications of completing research where the author is identified as the participant.
- Understand the principles of writing reflective topical autobiographical accounts from personal data sources.

Project Overview and Context

The condition of osteoporosis

This case is based on the research I completed for my doctoral studies. The area of focus was the condition of premenopausal osteoporosis. This case will start with a brief overview of the condition in order that the reader may then place the methodology decision making process in context.

Osteoporosis is a progressive, systemic, chronic skeletal disorder, characterised by the deterioration of bone mineral density resulting in an increased susceptibility to low trauma fracture (National Institute for Clinical Excellence, NICE, 2008). The condition traditionally affects post-menopausal females due to the impact of falling oestrogen levels at menopause and the resultant negative effect on bone mineral density (de-Souza, 2010). Fractures occur most often from the person falling from standing height or less, with rib or vertebral fractures occurring without a traumatic event, such as during coughing for example (Papaioannou et al., 2004). In 2006 it was estimated that over 200 million people worldwide had osteoporosis (Reginster & Burlet, 2006) with a bone fracture, due to osteoporosis, occurs worldwide every three seconds (International Osteoporosis Foundation – IOF, 2017).

Premenopausal osteoporosis is a poorly understood condition in which otherwise healthy, premenopausal women have very low bone mineral density. This makes them susceptible to low trauma fractures that are both painful and debilitating. Being diagnosed with a chronic condition at any age has been shown to have profound psychosocial implications for the individual. A diagnosis of osteoporosis for a premenopausal female is significant as the condition is most commonly associated with postmenopausal women. For a young woman, the age of diagnosis contrasts markedly from the common cultural paradigm for the condition, with its established health care pathway and support systems. There is a paucity of literature on the patient experience of osteoporosis and literature on the patient experience of premenopausal osteoporosis seems absent altogether. The aim of my doctoral study was to explore the previously undocumented experience of living with osteoporosis, as a young active female.

Coming to a Research Area

My interest in this research area came directly from one moment, when I was given a diagnosis of osteoporosis, at the age of 33. When my doctor gave me the diagnosis and followed it with the question “I suppose you want to know what we are going to do about this?” My answer of “No I want to know why I have it in the first place,” started an information seeking process that escalated into my research for my doctoral degree. As an educated patient – someone trained in musculoskeletal health, with access to university level search strategies and databases – the more I read, the more the ambiguities within the literature progressed my reading from that of patient, to that of a researcher, starting to piece together both the theoretical and knowledge gaps that were becoming so obvious to me.

The majority of literature associated with chronic conditions (such as diabetes, rheumatoid arthritis or chronic kidney failure) comes from a biomedical viewpoint. The emphasis is placed on understanding the condition, reporting how many people have it and investigating potential curative interventions. The literature on osteoporosis was no different. The focus of research to date had been the reporting of clinical areas such as the epidemiology of the incidence and predication of osteoporosis within populations (Delialioglu et al., 2009; Cauley, 2017), the epidemiology of fracture sites (Cummings & Melton, 2002), causes of osteoporosis (Fitzpatrick, 2002; Khosla et al., 2011), clinical characteristics (Cohen et al., 2009; Liu et al., 2010), factors affecting the achievement of peak bone mass in terms of prevention and treatment of low BMD (including pharmacology and to a lesser extent public awareness of the condition (Tanna, 2009; Chang et al., 2010). There was a lack of literature on the patient experience for those with osteoporosis and the research on premenopausal osteoporosis patient experiences seemed absent altogether. Yet, health care professionals have reported that patient experience literature evokes in them a far greater depth of awareness of conditions (Barry, 2001).

Starting methodological decision making

My age of diagnosis placed me 30 years younger than the traditional patient for the condition of osteoporosis. Between the ages of 32 and 34 I sustained three low trauma fractures associated with my osteoporosis; a wrist fracture from snowboarding in January 2010, a double rib fracture from being tickled in December 2010 and a stress fracture to my foot from jogging, in the spring of 2011. A lifelong diary writer, I wrote in my diary throughout my experiences of diagnosis and in the years following. Each of these experiences were significant in my journey towards my research study and directly impacted on the decision making process for my chosen methodology. My experiences within both the health care system and within my world of thoughts and feelings, and the resultant personal writing, demonstrated some of the complexities of being a non-traditional patient for a condition with such a strong cultural stereotype. So, with personal experience of being diagnosed with premenopausal osteoporosis and being positioned by the health care system as a non-traditional patient, a research question and resultant methodology was chosen that embraced a *researcher-as-participant* method to answer the following research question.

> How have I, a young active female, experienced living with premenopausal osteoporosis?

Section summary

- *As with many chronic conditions, the previous literature in the area of osteoporosis was predominately biomedical in nature.*
- *With personal experience of being diagnosed with osteoporosis in my 30s I was in a position to provide a first person account to enhance not only the qualitative literature in the field of osteoporosis but start the conversation about the experiences of non-traditional patients for conditions.*
- *Patient stories support the training of medical professionals in giving them a window into their patient's experiences of their conditions, rather than the tradition focus on the biomedical aspects.*

Research Design

Since Strauss and Glaser's (1975) seminal work researching chronic illness and quality of life, there has been a steady growth in studying the meanings and experiences of those with chronic conditions (Pierret, 2003). By storying moments of experience, an individual's emotional and subjective worlds are made accessible to others through an empathic connection (Erben, 1998), bringing meaning to their personal experience (Carless & Douglas, 2013). Research using illness stories (narratives) have covered a broad range of topics including chronic fatigue (Bulow et al., 2013); spinal cord injury (Sparkes & Smith, 2003); HIV (Ware, 2013); illness in the homeless (Hakanson & Ohlen, 2016); and endometriosis (de Souza Sao Bento et al., 2017).

My journey to choosing the most appropriate method, through which I could answer my research question, spanned many months. The research was initially termed an autoethnography as that was the only first-person methodology I was aware of when I started the research process, however the piece went through many iterations until the final auto/biographical method was formalized. Only through researching the founding philosophy behind potential researcher-as-participant methodologies did I feel I could truly defend my choice of method from criticism. What follows is a summary of that journey and the methodological decision-making process. For each method I use the following example of data from my PhD and how it would be interpreted using each of the three first person methodologies of autoethnography, autophenomenography and auto/biography.

> "I seem to be doing quite a lot of worrying at the moment. I feel a distinct lack of control over all of this and that's not a natural state for me to be in! You know what I think it is? Things have lost momentum. For the first 4-5 month (from rib fracture to my final London appointment) my life was scans, tests, waiting for blood tests, intense training and writing PhD proposals etc etc it was almost exciting for a natural information seeker such as myself (MORE INPUT!!!) but now the tests have stopped, I am on my own and for the next 18 months, until I can persuade them to scan me again, it's back to being in no man's land and I don't like it" (Thurston 2018).

Understanding Autoethnography

The first methodology considered as an approach for this research was that of auto ethnography. Ellis and Bochner (2011, p.742) define autoethnography as,

> "...autobiographies that self-consciously explore the interplay in the introspective, personally engaged self with cultural descriptions mediated through language, history, and ethnographic explanation."

It is a form of self-narrative that places the self within a social context (Reed-Danahay, 1997), stems from the field of anthropology in the 1970s, where researcher's field notes of their experiences of observing a culture, were added to the final research output (Reed-Danahay, 1997). The methodology transcends the narration of self, to engage in cultural analysis and interpretation (Chang, 2008). Chang (2008, p.48) states that autoethnography should be,

> "ethnographic in its methodological orientation, cultural in its interpretive orientation and autobiographical in its content orientation."

To acknowledge these three influences of ethnography, culture and autobiography, each influence should be overt in both how the data was collected, the type of data collected and how the data is interpreted. If my PhD was to be autoethnographic then the methodology would have to be ethnographic in nature. Ethnography involves data collected through observation (Reed-Danahay, 1997). This observation is traditionally of a cultural group, but, for autoethnography, the observation would be of the self, using autobiographical data collection methods such as the diary data presented above.

For an autoethnographic research project, the interpretation of that data would need to be through a cultural lens. My experience of premenopausal osteoporosis could either have been an adjunct to the stories of others with my condition (that is, the culture being ‘observed’ or explored would be those with premenopausal osteoporosis) or treated as a standalone story from which the culture of being a non-traditional patient for a chronic condition could be explored alongside the stories of others who were also nontraditional patients, for example male breast cancer patients, or those with early onset of menopause. The social culture would have to involve acknowledging the social context in which the story is presented, that is, the National Health Service (NHS) between the years of 2011 and 2017.

Using a cultural lens to analyse the quote from my PhD above, the social/cultural analysis might look at the perceived lack of aftercare appointments for chronic conditions, (“…now the tests have stopped, I am on my own…”) or the lack of patient involvement in clinical decision making within the NHS during that time (…”I feel a distinct lack of control over all of this…”).

Health autoethnography has developed in the last 20 years, to provide a voice to those diagnosed with chronic conditions (Ettorre, 2010) but the need for visible ethnography and cultural interpretations did not align with the aim and research question for my doctoral research (with its goal of providing an understanding of the experience of living with a condition rather than the cultural implications). Lived experience work aligns with the philosophy of phenomenology and as such the potential for exploring an experience of the self, grounded within this philosophy was then explored.

From Phenomenology to Autophenomenography

Within phenomenology, a greater understanding of the lifeworld or lived experience is sought through the consciousness of the experiences rather than analysis of the given in an objective manner (Smith, 2009). Modern phenomenology emerged at the beginning of the 20th century from the work of Edmund Husserl (1859–1938) which developed Wilhelm

Dilthey's (1833-1911) works on how individuals engaged in experiential life. Different forms of phenomenology have developed since its original works: Constitutive/transcendental (descriptive) phenomenology; Hermeneutic (interpretive) phenomenology and Existentialist (embodied) phenomenology (Allen-Collinson, 2009). The use of a single case as the basis of an interpretive phenomenological enquiry can be "especially powerful" given the depth of analysis that can be achieved (Smith et al. 2009, p.51). Within caring research, phenomenology is concerned with,

> "understanding the meaning that people give to their everyday experiences, to gain a deeper understanding of patients' and health care professionals' experiences of illness and caring" (Larsson and Holstrom, 2007, p.59).

A phenomenological study, in which the focus of the single case experience is that of the researcher, was first proposed by Gruppetta (2004). Gruppetta proposed that if the researcher was completing a researcher-as-participant study focusing on a phenomenon rather than a cultural place (as is the case for the more commonly seen autoethnography) then the more appropriate methodological term would be autophenomenography (see Ettorre, 2006 and Ettorre, 2010 for examples).

For a study using autophenomenology, the resultant phenomenological analysis would present the essence of the phenomenon, the element without which the phenomenon would not be what it is (Strandmark & Hedelin, 2002). By immersing themselves in the data, the researcher can reduce that data to its essence, and for my PhD project this would be the essence of being a young woman with premenopausal osteoporosis. Initially, the full narrative of the experience is recorded;

> "I seem to be doing quite a lot of worrying at the moment. I feel a distinct lack of control over all of this and that's not a natural state for me to be in! You know what I think it is? Things have lost momentum. For the first 4-5 month (from rib fracture to

> my final London appointment) my life was scans, tests, waiting for blood tests, intense training and writing PhD proposals etc etc it was almost exciting for a natural information seeker such as myself (MORE INPUT!!!) but now the tests have stopped, I am on my own and for the next 18 months, until I can persuade them to scan me again, it's back to being in no man's land and I don't like it" (Thurston 2018),

yet the phenomenological analysis would reduce this narrative down to the essence of that lived experience, for example, *that being a young woman with osteoporosis is a lonely and uncertain time, characterized by information seeking and a desperate need to try to regain control.*

Autophenomenography was a potential methodology that could satisfactorily address the research question for this present research. However, from the biomedical literature we know that bone formation (completed by the age of 30), and osteoporosis (being an accelerated degeneration of that bone) are both influenced by factors present in a person's lifecourse/biography. The diagnosis therefore needed to be placed within the context of that life course and biography of the individual. Biographical methodology enables the researcher to look beyond the phenomenon and essences of the experience of premenopausal osteoporosis and explore the life of the individual as a whole entity, presented as a full narrative story to which others might relate.

Auto/biographical Research

"Lives and their experiences are represented by stories…" (Denzin, 1989, p.91).

The term autobiography comes from the Greek *autos* (self), *bio* (life) and *graphos* (to write) and so can be literally translated as self-life-story (Johnstone, 1999). It is important at this stage to highlight the forward slash (/) in the auto/biographical research method as it marks "the interrelation between the researcher's own life – autobiography – and the biography of the researched subject” and others who feature in their accounts (Roberts, 2002).

When used as a research method, the aim of auto/biography is not to render true accounts of the self but to render an account of the lived experience of the self that advances shareable understanding of common human experiences (Jones, 2003). The aim of creating a shareable understanding of common human experiences can only be measured as having been achieved if the reader is able to read themselves into, and be touched by, the final report through, the use of their imagination. Without imagination, there is no knowledge (Kant, 2011). It is the “reconstructive imagination” (Erben, 1998, p.10) initially proposed by Hume (1711-1776) as “sympathy” that is fundamental in understanding features of shared understanding.

> “No quality of human nature is more remarkable, both in itself and in its consequence, than that propensity we have to sympathize with others, and to receive by communication their inclinations and sentiments, however different from or even contrary to our own” (Hume, 1978, p316).

Through writing a research project using auto/biographical methodology there is the ability to prompt a shared understanding through both the distinctness and the connectedness of individual’s lives: “person A will never be person B” yet “person A can ‘recognise’ the narrative of person B” (Erben, 1998, p.15). The methodology of auto/biography would allow me to use my data to create a narrative describing the time of my life that was the focus of my research, that others could read with empathy and resonance (Erben, 1998). It would also allow me to set that moment in time within the broader context of my biography in its entirety, an element that was important given that bone density is affected by events in the lifecourse. Using Reflective Topic Autobiography, in particular (Johnstone, 1999), allowed me, the researcher, to reflect on the themes that were evident within my data. Within the data extract presented for analysis within this paper, these themes could be classified as ‘information seeking’, ‘uncertainty’, ‘control’ and ‘loss’ for example, with each theme then being explored within the broader context of time, biography, society and history (Erben, 1998) to provide an interpretation that transcends the topic and allows relatedness with others on a human level.

Coming to the Most Appropriate Method

For autoethnography, the research aim is to provide an account of a group from an insider, first-person perspective, where the author is an active member of the group or culture being studied. The research question for my research focused on a singular reality, a single exploration of the idiographic nature of osteoporosis, for one individual, rather than a cultural study. Having ruled out autoethnography as an appropriate methodology, experiential methodologies focusing more on the individual and their experience as their singular truth were explored. Autophenomenography, with its origins in phenomenology, would appear to be a suitable methodology in answering the research question however, the philosophy of phenomenology is to identify the essence of the experience without which the experience is not what it is. This narrowing down of the experience is quite the opposite to auto/biographical methodology which looks to place that experience within the life story of the individual and relate the experience to the historical and social world in which the individual has lived. “A life that is studied, is the study of a life in time” (Erben, 1998, p.13). The condition of osteoporosis is biographical. Peak bone mass is achieved by the age of 20 (Heaney et al., 2000) with a small margin for improvement in some cases for the next eight years (Chew & Clarke, 2017). Any interruption to the bone formation period, either through illness disrupting bone physiology or lifestyle factors such a limited diet, disruption to reproductive hormone production, immobilisation, etc. could have a devastating impact on the risk of fragility factors and osteoporosis in adulthood (Heaney, 2000). Exploring a diagnosis as a snap shot in time would not honour the nature of both the condition and individual and might limit the resonance a reader may feel through a deeper understanding of the biographical journey that took the affected individual to that diagnostic point and beyond.

Completing the Autobiography

The auto/biographical approach I undertook, was influenced by the work of Denzin (1989); Moustakas (1990); Erben (1998); Zammit (1998); Johnstone (1999) and Exley and Letherby (2001) amongst others. These influences were both theoretical (Denzin, 1989; Erben, 1998; Johnstone, 1999) and emotional, through the power of the stories told within their research (Moustakas, 1990; Zammit, 1998; Exley & Letherby, 2001). The method was developed as a means of enabling the telling of the illness story through the benefit of time and reflection (Johnstone, 1999).

The primary sources of data on which the auto/biographical account was based, were my personal diary and an anonymous blog entitled "*My Bones Won't Break Me*" (Hawkes, 2012) I started at the time of my diagnostic journey. My diary entries were all written in the moment or at the end of a day in question to ensure the distance between the occurrence that had prompted the data collection, and the data collection itself has been minimized. The hope was that this led to more authentic, accurate and vivid accounts (Rodriguez & Ryave, 2002).

My final diary entry associated with my osteoporosis was February 2014, almost 3 years post diagnosis, in which I commented that I felt no further compulsion to write to process my circumstances. This provided a natural end point to the data collection process. A total of 31 blog entries were posted. The final post on the blog was October 29th, 2012. After this point, I continued to write private diary entries however I did not feel the need or desire to continue my journey in the public domain.

The process of creating a reflective auto/biographical account

The following steps were taken to create a reflective topical auto/biography for this research study and mirrored those presented by Johnstone (1999) in her original proposal of the method as being of use to health-based research.

- Data Collection: All diary and blog entries for the period of January 2011 to December 2013 were collated and integrated in a word document and placed in chronological order.
- These entries were then linked to create a continuous account of that period in time, as it was recorded at the time, using the dates of the entries as subheadings for the account.
- The narrative account (that was the result of the above process) was then reviewed by the two PhD supervisors, with the aim of gaining feedback as to the readability of that account.
- The narrative was then edited to progress the account from an ‘in time’ narrative containing repetition and chaos (Frank, 1995), to a more readable account. This was achieved through the removal of entries that were not deemed to be related to the research questions, removing repetition between diary and blog entries documenting the same event, and through storifying the data through the use of event subheadings to create a plot to the story.
- The processes of collating, ordering, linking and reediting (steps two to four above) were ones of Immersion in which I was deeply embedded in the story of my experience.

- A three-week period of Incubation (time away from the research), was then taken so that I had the space and time to reflect on the main themes of the narrative account.
- Each of these themes were then written as an interpretation of the narrative to demonstrate my reflections on my experience from a position of the present (six years post diagnosis). The writing up of these reflective themes used direct quotes from diary and blog entries - the original data from which the narrative was created.
- The final stage employed within this present research was one of exploring each theme in relation to the broader literature on experiences of osteoporosis and other invisible chronic illnesses. This stage was included to ensure the inclusion of the scholarship requirement of PhD study and was not part of Johnstone's (1995) original steps in writing a reflective topical autobiography

Section summary

- *There are several first person researcher-as-participant methodologies available to a researcher who wishes to use their own experience as data.*
- *Choosing the right methodology and being able to justify that choice, should involve a deep exploration of the founding philosophy and methodology to place the research within the correct ethnographic, phenomenological or biographical emphasis depending on the research question.*
- *Autobiographical work must be robust and follow a systematic procedure. The final account should allow connectedness with the reader and stimulated imagination and resonance so that the reader may empathise with the research on a human level.*
- *Research-as-participant research should not be carried out as a therapeutic exercise. The connection between the individual case and the social/political and historical context must be overt.*

Method In Action – Process and Ethics

To complete an auto/biographical piece of research was a journey that was both rewarding and challenging. The process was definitely made easier by having diary entries recorded at the time of my health journey. These entries allowed the first narrative to be produced from which the final reflective pieces could be explored. However this first narrative was a chaotic piece of prose that needed several editing rounds to create a coherent piece that would be readable by an audience. The process of immersion was intense, and quite overwhelming at times. To be that focused on a period of my life that was challenging was emotionally exhausting. Yet the period of incubation sparked an exciting progression in the research journey where I could achieve distance from the experience and reflect on the core experiences in a thematic way that then allowed exploration of those themes in relation to the broader chronic illness literature. The reflective topical autobiographical approach set out by Johnstone (1999) gave structure to a process that could otherwise become narcissistic and meaningless through being so individualized that no reader could draw any shared meaning or understanding from the story.

The completion of the auto/biographical research raised an important ethical issue however. Traditionally systems are in place to protect participants through the application of confidentiality, anonymity, informed consent and the right to withdraw from the research at any point. Within researcher-as-participant research, the anticipated guidelines for ethical considerations are somewhat null and void. Anonymity is automatically waivered when a researcher identifies themselves as the participant within their research. Qualitative researchers must provide detailed, accurate accounts of the social world they are exploring yet this provision can breach confidentiality via deductive disclosure (Kaiser, 2009).

Although I have written the reflective topical autobiography based on my personal experiences, the people within that story have the right to confidentiality and anonymity (Tolich, 2010). Individuals may be identifiable by others who are not involved in the study or by family members who read the results of the study. Hiding identities of others through the use of pseudonyms is applicable to a certain extent yet characters are identifiable by familial relationship such as mother, sister etc (Sabar & Sabar Ben-Yehoshua, 2016). Because of these risks, people and places referred to within my thesis were de-identified. People and places within the health care system were termed 'the doctor' and 'the hospital' etc. Family members were termed 'my sister' or 'my brother' and were given the opportunity to review the story in which they appeared. Each family member was given an informed consent form to complete to provide his or her written permission to feature within the thesis. Confirmed through written consent, other key characters, such as my husband, for example, gave permission for their first name to be used.

In terms of myself, to revisit traumatic events was of concern in terms of my own mental wellbeing, but I felt the story of my experience needed to be told to add to the shareable understanding of human experiences. The process was not without pain, upset and isolation. The passage of time between the experiential data collection (in the form of diary entries etc in 2011 to 2013) and the completion of the reflective topical autobiography (in 2017) served to make this process manageable. My supervisors were always available to me should I have found myself in a position where I was unable to process the intensity of the experience by myself.

My unwillingness to re-live the experience however, came through in my account of that time. I presented a story 'told,' rather than a story 'shown' such as one would expect in a novel for example with immersive scene setting and dialogue. Perhaps with a greater passing of time, a more immersive version of the story could be created without psychological harm to either myself or my family.

Section summary

- *The very nature of writing an auto/biographical account means that you are identifiable as the participant.*
- *Systems are in place to support research participants and special attention must be paid to this area of concern when the researcher is writing about themselves and their own health experiences.*
- *The use of pseudonyms does not protect those identifiable by familial terminology, so a further layer of consent needs to be sought from identifiable others who feature within the auto/biographical narrative.*

A method not for the faint hearted

Patient stories allow a deeper, more insightful and at times distressing account of the patient's experience of their condition and their health care journey but to be a researcher who was now exposing their private world to add to a wider understanding of a health care process, was unexpectedly difficult. Publically I am an academic at a UK Higher Education Institution, Programme Leader for a professional Bachelors degree and had a 10 year professional career in the field of Sport Rehabilitation prior to my move to Higher Education. Until eight years ago my only concern with the condition of osteoporosis was the chapter that featured in my sports injury text books.

The process of choosing to complete my PhD within a research area that was so personal, had implications for me personally but also more broadly. I had always had a strong relationship with writing during times of adversity or upset, and so it was quite natural for me to be writing at this time, recording the chaos of my everyday existence. The nature of choosing a researcher-as-participant methodology, however, meant that whilst I wrote about my experiences and explored them in relation to broader concepts, there came a point when the commitment to the PhD conflicted directly with my desire to move forward from the upsetting uncertainty of my diagnosis. I wanted to forget my condition yet my research caused me to have to revisit and confront it daily. Similarly trying to combine this part time research with my position as an academic was particularly difficult. I had a busy timetable spread out across the working week so had to commit to working on my research during any short gaps during the day. With a topic of this nature, I found it almost impossible to be able to fully give myself to either of these commitments:

It was only in March 2017 that I had enough distance between me and the diagnosis in 2012, to be able to acknowledge and embrace the auto/biographical method as that was the most appropriate for answering the research question. Previous to that I had continually tried to keep the data and the experience at arm’s length. I initially wanted to complete thematic analysis on my diary data and therefore code the diary entries so that I didn’t actually have to think about them as being my words, just words to be analysed! Having read both the history and application of auto/biographical work and been involved in a biographical study group (see Cooper, Oliver, Podee & Thurston 2017), I could finally appreciate my diagnosis was not a distinct point in time ring fenced from the rest of my biography and so could not be treated as such within my research..

The biggest implication for me, however, has been one of control and disclosure. Whilst changing my name because of marriage has allowed me to distance myself from this part of my life (as I wish to be known for my professional and academic achievements rather than for my condition), by writing the PhD thesis I will forever be recorded in archives as having osteoporosis. The diagnosis of an individual with a chronic condition has been shown to result in a new label of identity being attached to that person, that of their condition. Patients have reported both being seen by others, and being seen by themselves, as their condition rather than a person with a condition, for example, those with epilepsy found themselves feeling like an ‘epileptic’ rather than a person who happens to have epilepsy (Raty & Wilde-Larsson., 2014).

Finally, I am an academic within the competitive world of Higher Education. When I first mentioned I was completing a ’researcher-as-participant’ PhD, senior colleagues in my former Faculty, told me I was making myself unmarketable should I wish to get promotion or move institution as the idea of a PhD was to gain broad research skills that could not be achieved if researching oneself.

My ultimate hope for my research was that the dissemination of my experience would support others who find themselves either a biomedical stranger, those who have been diagnosed with premenopausal osteoporosis; those who are training within the health care profession; or a researcher contemplating a researcher-as-participant study for their research.

> “Once the research becomes a product, the writer is vulnerable. When doing research on an issue with which one has a personal involvement and when writing in part about oneself, it is easy to feel that criticism is directed not only at your academic work but at you personally” (Letherby, 2000, p.107).

Section summary

- *Completing a researcher-as-participant methodology may have unexpected implications for the researcher both in terms of their wellbeing and their researcher identity moving forward.*
- *By writing an auto/biographical account the researcher is forever giving up ownership of their story to the reader, a process that can be conflict over the control of dissemination.*

- *Whilst writing has been shown to be a therapeutic process, the need to repeatedly revisit a period in one's life can be a part of the auto/biographical process that may conflict with one's desire to move forward from that period of their life.*

Conclusion

Researcher-as-participant methodologies, utilising single cases as data collection, have previously been contested, primarily for their lack of theory and their relation to subjectivity and their self-indulgence (Sparkes 2002). The most predominant criticism of these methods is the lack of generalisability of the single case to broader populations in order to legitimise the methods as proper academic research (Sparkes 2002). These criticisms appear as part of the wider ongoing debates between qualitative and qualitative approaches and, in specific relation to doctoral work, there are debates on what constitutes academic knowledge and who grants it legitimacy (Dumitrica 2010). Legitimacy, however, is contextual. In addition to the qualitative criteria for achieving rigour set by Lincoln and Guba (1985) and Vaismoradi et al. (2013) (credibility, dependability, confirmability and transferability) researcher-as-participant work looks for reflexivity, impactfulness, aesthetic merit, a substantive contribution and the degree to which the text clarifies a lived reality (Holt 2003).

Utilising autobiographical methods, and reflective topical autobiography, seven reflective themes were produced from my illness experience data: Engagement with the medical profession; information seeking as an educated patient; managing invisibility and disclosure; social interaction; the impact on physical activity; a stranger in a biomedical land; and the emotional journey. The experience of living with premenopausal osteoporosis was found to be a disruptive and dehumanising one. Each element of the experience was impacted upon through the resonance of biographical and emotional echoes from biographical antecedents, such as life experiences, coping resources and personality. These echoes drove the journey through diagnosis and subsequent living with the condition and reinforce the idiographic nature of chronic illness experiences.

Through completing research using a single case that was my own was an exposing process and one that did not come without its challenges. The resultant research however is the first to highlight the experiences of a premenopausal female, and through exploring the findings in relation to broader literature, links can be made to the experiences of other non-traditional patients for health conditions, highlighting the need for personalized health care practices rather than 'condition specific' treatments regardless of the individuals uniqueness. The findings have demonstrated that chronic conditions come with them fear and uncertainty yet these emotions are exacerbated in those for whom a condition associated with old age, has come into their lives during earlier adulthood. The personal story is a powerful tool yet it must be used to enhance shareable understanding rather than be written for any therapeutic or self-serving purpose.

Section summary

- *A chosen methodology must always be the most appropriate way to answer the research question.*
- *In some cases, in order to advance a shareable understanding of a health condition, an auto/biographical methodology is the most appropriate one.*
- *Through an in depth reflection on, and analysis of a period in the researcher's health journey wider sociological issues can be brought to light.*

Classroom Discussion Questions

1) There are some key differences between the three researcher-as-participant methodologies of autoethnography, autophenomenography and auto/biography, particularly in terms of how data is interpreted. For each of these three methodologies

discuss where / on what, the emphasis for the interpretation section of a research project should be, particularly in relation to the ultimate aim of each methodology.

2) One of the key issues with auto/biographical research is the ethical implication of identification of others who feature as part of your story. Discuss how you might address this issue in relation to a specific story you might want to tell, firstly by identifying the others and then formulating a strategy to address their right to anonymity.
3) Auto/biographical research can be based on 'in time' data (collected during a life event), or retrospective data as one reflects and addresses an event in the past through memory and recall. Discuss the implications for each mode of data collection (in time versus retrospective) on quality criteria that can be used for qualitative research.

Multiple Choice Quiz Questions

1) *For which of the following is there a need to address how a personal experience relates to a cultural group?*
    a. *Auto/biography*
    b. *Autoethnography - CORRECT*
    c. *Autophenomenography*
2) The aim of biographical research is to render an account of the lived experience of the self that advances shareable understanding of common human experiences. This can be achieved through which human quality?
    a. *– Imagination - CORRECT*
    b. *Judgement*

3) *QuestioningThere are set steps to follow in completion of a reflective topical autobiography (Johnstone 1999). What is the correct order for those steps:*
    a. *Immersion, incubation, data collection*
    b. ***Data collection, immersion, incubation - CORRECT***
    c. *incubation, data collection, immersion*

Declaration of Conflicting Interests

The Author(s) declare(s) that there is no conflict of interest.

Further Reading

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Web Resources

https://www.britsoc.co.uk/groups/study-groups/autobiography-study-group/

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