‘My Bones Won’t Break Me.’

A reflective topical autobiography exploring the experience of living with premenopausal osteoporosis.

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Copyright statement

Abstract

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, therefore, 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 this study is to explore the experience of living with osteoporosis, as a young active female.

Autobiographical methodology was employed utilising a reflective topical autobiographical approach. Data included personal diary and blog entries over a two year period, from pre-diagnosis, to 21 months post diagnosis. This allowed the breadth and depth of the experience of living with premenopausal osteoporosis to be captured through storytelling.

Seven reflective themes were produced from the 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.

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Abbreviations

BMD	Bone Mineral Density
DXA	Dexa Scanning
ISCD	International Society of Clinical Densitinometry
NICE	National Institute of Clinical Excellence
NOF	National Osteoporosis Foundation (International)
NOS	National Osteoporosis Society (UK based)
OP	Osteoporosis
RTA	Reflective Topical Autobiography
WHO	World Health Organisation

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Finally, to our daughter…As I complete this work you have just turned three years old. All you have known is a Mummy, distracted by the demands of PhD study – I will now have time for that one extra story at bed time.

CHAPTER 1: INTRODUCTION

1A. Overview

This study aimed to explore a young woman's experience of living with premenopausal osteoporosis. Osteoporosis is a progressive, systemic, skeletal disorder, characterised by the deterioration of bone tissue. This results in an increased susceptibility to fracture (National Institute for Clinical Excellence, NICE 2008). Osteoporosis is most prevalent in postmenopausal females who experience an accelerated loss of skeletal density due to the drop in oestrogen that the menopause brings. The figure below demonstrates the deterioration of bone tissue associated with osteoporosis. The osteoporotic bone (the right hand picture) has broken down to such an extent that the bone becomes highly susceptible to fracture (Melton III 2000).

Figure 1: A representation of the progressive thinning of bone (from left to right) that is the presenting characteristic of osteoporosis (National Osteoporosis Society ca. 2018).

In 2006 it was estimated that over 200 million people worldwide had osteoporosis (Reginster and Burlet 2006). 22 million postmenopausal women, aged 55 years or older, present the disease and, of these, 78% are not diagnosed (de Souza et al 2010). Osteoporosis is described as a silent disease, as it has no presenting symptoms until an individual sustains a fragility fracture, or presents with a spinal curvature (Papaioannou et al. 2004). A bone fracture, due to osteoporosis, occurs worldwide every three seconds (International Osteoporosis Foundation - IOF 2017). Fractures occur most often from the person falling from standing height or less. Rib or vertebral fractures can occur without a traumatic event, such as during coughing (Papaioannou et al. 2004).

Bone loss leading to low bone density is a natural process for both sexes. Anyone who lives long enough will eventually present with osteoporosis. It is the accelerated loss of bone density (Ilona et al. 2010; Liu et al. 2010) or a systematic and lifelong presentation of low bone mineral density that causes worldwide concern and incurs high healthcare costs (Kanis and Johnell 2005). It can also, in some cases, lead to early death in the elderly population (Goldmann and Horowitz 2003).

The most well documented consequence of having osteoporosis is the increased risk of fracture, due to loss of peak bone mass (Melton III 2000). Women lose between 30 and 50% of their peak bone mass over their lifetime (Riggs and Melton 1995). After menopause, 40% of white females (the ethnic population found to be most affected by low bone density) will suffer one or more fractures due to osteoporosis, with fractures of the hip making up 17.5% of those fractures sustained (Melton III 2000). Ten to twenty percent more women die than is expected for their age within the first year following a hip fracture with the excessive mortality being even higher in men (Riggs and Melton 1995). Severe vertebral fractures, however, affect 10% of postmenopausal white women and cause disfigurement, persistent pain and significantly reduced quality of life (Gold et al. 1996; Melton III 2000; Ettinger et al. 2013).

Osteoporotic fractures to the spine, wrist, feet, and ribs, account for over 2 million outpatient visits per year in the USA and 600,000 accident and emergency incidents (Sanchez-Riera et al. 2010). Within the European Union in 1998 patients with osteoporosis occupied half a million hospital beds – a figure expected to double by 2050 (Delmas & Fraser 1999). These fractures not only have an impact on the affected individual concerning pain, disability and a decreased quality of life but there is also a monetary cost to the services involved in the individual's care and treatment (Thomas 2010). It was estimated that within the European Union alone (in the year 2000), that 3.79 million osteoporotic fractures occurred (Kanis and Johnell 2005). As a result of these fractures, the combined direct costs to the health services in these countries are estimated at 32 billion Euros for that year (Reginster and

Burlet 2006). This figure is due to rise to €77 billion by 2050 due to demographic changes leading to an ageing population (Kanis & Johnell 2005).

The direct estimated economic burden of new, and prior fractures, is estimated as £3,496 million each year, with an increase of 24% expected by 2025, to £5,465 million (Svedbom et al. 2013). Data shows that the pre and post-fracture cost for women over 50 years old is between £1015 and £1598 for vertebral fractures alone (Greendale and Barrett-Conner 2001). Hip fractures, in particular, require an extensive period of expensive hospitalisation. These fractures are also fatal in 20% of cases and result in permanent disability in 50% of those who sustain such a fracture (Greendale and Barrett-Conner 2001). Only 30% of patients fully recover to pre-fracture function (Sembo and Johnell 1993). Following hip fracture, it has been reported that only 15% of patients could walk across a room unaided and 24% of those over the age of 50 died in the year following their fracture to the hip (Ahlborg et al. 2004). Within otherwise healthy females, hip fractures increase their relative risk of dying six-fold and vertebral fractures increase this risk nine-fold, compared to fracture free periods, with half of these deaths being within a year of fracture (Ahlborg et al. 2004; Cauley et al. 2005). Within the United Kingdom, 1,150 people die each month from the consequences of hip fracture (Hernlund et al. 2013). The majority of those at high risk, who have already had at least one osteoporotic fracture, are neither identified nor treated (Nguyen et al. 2004).

Osteoporosis is a long-term chronic condition. As a result, it has both clinical and public health implications. These are due to the cost of pharmaceutical interventions, hospitalisation treatments and the social burden subsequent immobilisation instigate (Kanis and Johnell 2005). The condition causes worldwide concern and incurs high healthcare costs (Kanis and Johnell 2005; Ilona et al. 2010; Liu et al. 2010).

Living with a chronic condition not only poses a potential threat to the individual's health and well-being but also requires continual adjustment within all aspects of daily life. These changes are needed due to physical suffering, impairments in

functioning capacity and worry, not only on the part of the individual but also the family (Mok and Tam 2001; Lundman and Jansson 2007). Living with osteoporosis and non-traumatic fracture risk can result in serious psychological morbidity (Hallal 1991) with pain, role loss and physical limitations being experienced to varying degrees by those with the disorder (Roberto 1988; Thomas 2010). There is a considerable and adverse psychosocial impact on the health-related quality of life of those with osteoporosis when compared to age-matched individuals (Randell et al. 2000). It is essential to understand the unique dimension of experience of a young premenopausal woman with this condition, as she sits outside of this traditional demographic. This study explores the implications of the condition on a young woman's life. That young woman is me.

This introductory chapter continues by describing my/the author's research journey, which led to the development of the current study. The background to the study is contextualised as elements of the biomedical literature relevant to premenopausal osteoporosis are presented. The methodology is outlined, and the research question proposed. The chapter concludes with a summary outline of the chapters in the thesis.

1B. The Author's Research Journey

My training as a professional sports injury rehabilitator, my position as an Academic within a Higher Education Institution and my experience of being diagnosed with osteoporosis at the age of 33 years old have all influenced this research journey. My age of diagnosis placed me 30 years younger than the traditional patient for this condition. I have 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. I also started a blog as I awaited my diagnostic results to

educate others about the condition and plot my experiences. All of these experiences were significant in my journey towards this study and eventually in the chosen methodology. My experiences within both the health care system and within my world of thoughts and feelings, and the resultant writings, demonstrated some of the complexities of being a non-traditional patient for a condition with such a strong cultural stereotype.

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 have been 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?

This chapter continues by drawing on the biomedical academic literature for the condition of osteoporosis, to set the contextual background to the study and justify the chosen research methodology.

1c. Osteoporosis

i. Types of Osteoporosis

There are three categories of osteoporosis: Primary, secondary and idiopathic osteoporosis. Primary osteoporosis is the most common presentation of the condition and is expected by the normal ageing process (Gold et al. 1991). The natural history of osteoporosis demonstrates that bone density increase and decrease are typical and expected patterns throughout the lifespan as can be seen in Figure 2.

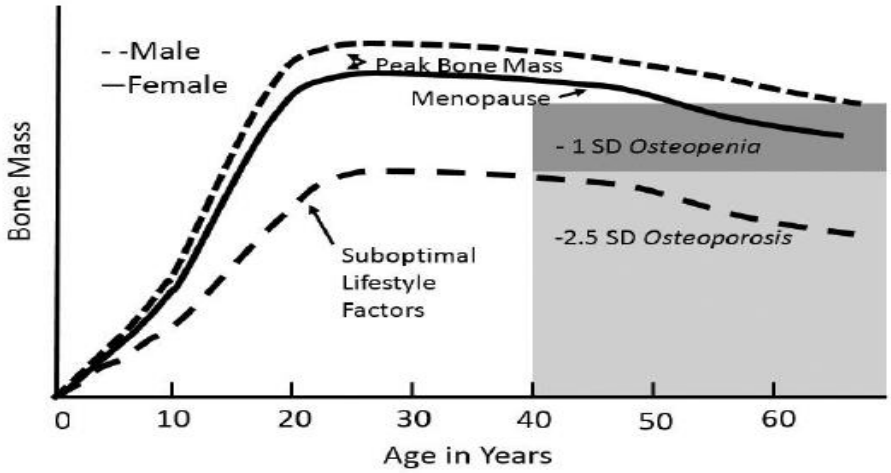


Figure 2: The Natural History of Osteoporosis (Janz & Francis 2015)

Skeletal peak bone mass is reached between 20 and 30 years of age after which there is a natural and expected decrease in bone density for both men and women. In women, there is a further increased rate of decline post menopause (Janz and Francis 2015). Measured through Bone Densitometry (DEXA scan), bone mineral density (BMD) is measured as a T-score; the standard deviation rating below the average BMD score for a young adult. Originally a BMD DEXA reading more than 2.5 standard deviations below the expected bone density for a particular age group, would result in a diagnosis of osteoporosis to made (World Health Organisation - WHO 1994). The WHO then provided further guidance for the assessment of osteoporosis to include a risk factor score called FRAX (a calculation to determine a 10-year probability of fracture), along with height and weight (WHO 2007). Each of these guidance documents referred to postmenopausal females only.

Premenopausal osteoporosis is evident in two forms: Secondary osteoporosis and idiopathic osteoporosis. Secondary osteoporosis can occur at any age, within both sexes, and is defined as bone loss that results from specific clinical disorders (Fitzpatrick 2002). This form of osteoporosis can often be reversible (Fitzpatrick 2002). Ninety percent of young men and premenopausal women with osteoporosis have a secondary cause for their bone loss, such as an underlying disorder (e.g., hypogonadism) or a medication exposure (e.g., glucocorticoids, antiepileptic drugs). These secondary causes have either interfered with the acquisition of peak bone

mass, or caused excessive bone loss after peak bone mass has been achieved (McLendon and Woodis 2014; Langdahl 2017). Endocrine disorders, such as hyperthyroidism (Mosekilde et al 1990) and type 1 diabetes mellitus (Reddy et al 2001); adverse effects of medications in particular glucocorticoids (Canalis and Giustina 2001), periods of immobilisation (LeBlanc 1990) and disorders of the gastrointestinal tract, for example malabsorption syndromes (Meyer et al 2006), are all associated with low BMD. Once the secondary cause of the osteoporosis is identified and rectified, the individual's bone density may increase. Secondary causes of osteoporosis, however, are not routinely considered in many patients. Only 20% of patients presenting with known risk factors being offered further investigation (Fitzpatrick 2002).

Idiopathic osteoporosis (IOP) is:

> "a poorly understood entity in which otherwise healthy, premenopausal women have low trauma fracture and very low bone mineral density" (Liu et al. 2010, p.1496).

Forty to sixty percent of young males and females with fracture and low bone mineral density diagnosed by DXA scan have no discernible cause (Moreira et al. 2000). Idiopathic osteoporosis (where no risk factor or cause can be attributed) was first described by Fuller Albright in 1944 and is an uncommon condition. The condition mostly affects Caucasians who present in their mid-30s with one or more low trauma fracture (McLendon and Woodis 2014). There is currently no approved therapy for idiopathic osteoporosis in premenopausal women (McLendon and Woodis 2014).

ii. Defining Osteoporosis

The ambiguities in defining osteoporosis are of acute importance for the premenopausal female with low bone mineral density. There are two primary definitions for osteoporosis provided by The National Institute of Clinical Excellence (NICE) definition and the World Health Organisation (WHO). The full definition provided by NICE (2008) is:

> "A progressive, systemic skeletal disorder characterised by low bone mass and micro-architectural deterioration of bone tissue, with a consequent increase in bone fragility and susceptibility to fracture" (NICE 2008).

While the NICE definition is comprehensive in its inclusion of the temporal, accelerated and degenerative components that are characteristic of osteoporosis, the most common and widespread definition for osteoporosis used within literature is that established by senior authorities acting on behalf of the World Health Organisation (WHO). In 1994 the WHO proposed the term *densitometric osteoporosis*, defining a condition category applicable to postmenopausal white women (the category was not extended to women of other ethnicities). This definition focused on an individual's bone mineral density (BMD) as determined through Dual X-Ray Absorptiometry Scanning (DXA) data of the lumbar spine and hip. The result of this measurement is a reading of the density of the bone in grammes per centimetre squared (g/cm2). The processed BMD reading for an individual is presented as a comparison of their values, to those of healthy young women at their age of attainment of peak bone mass. Results of DXA scanning are given as standard deviations (SD) away from the normative data and are termed the 'T-score'. WHO definitions of normal BMD, osteopenia, osteoporosis and established osteoporosis are shown in the table below.

Diagnostic Category	**Definition**	**T score**
Normal bone mass	BMD<1SD below the average of young adult mean	>-1SD
Osteopenia	BMD 1 to 2.5 SD below the average of young adult mean	-1 to -2.5 SD
Osteoporosis	BMD >2.5SD below the average of young adult mean	<-2.5 SD
Established osteoporosis	BMD > 2.5 SD below the average of young adult mean and the presence of one or more fragility fractures	>-2.5 SD

Table 1: World Health Organisation Diagnostic Criteria for Osteoporosis (WHO 1994)

The WHO has stipulated that osteoporosis is present if the individual's T-score is more than 2.5 standard deviations below normative T scores (WHO 1994). Due to the lack of data concerning the relationship between BMD and fracture risk in men and non-white women, the WHO has not established a definition of osteoporosis for these demographics (Kanis 2005). The WHO definition, in comparison to the NICE (2008) definition, has no recognition of the continued and accelerated bone loss of the osteoporosis. Osteoporosis has a degenerative element to it, in that bone loss exceeds that experienced by the average population.

While WHO T-scores have been used throughout literature to categorise individuals into bone mineral density groups for the diagnosis of osteoporosis or osteopenia, Lewieki (2008) highlights that this most commonly used definition for osteoporosis is fundamentally flawed. These scores were never intended to be diagnostic or definitive (Lewieki 2008). The scores were produced to assist epidemiologists in evaluating and comparing populations of patients in a reportative way rather than become diagnostic criteria. As far back as Sandor et al. (1999), there were arguments that the WHO categorisation was too simplistic and required upgrading to add indices associated with the representation of the distribution of bone and its minerals and further risk factors like fall biomechanics. The WHO definition, however, remains unchanged to this day.

Due to the lack of uniformity in the definition of osteoporosis, there has been a resultant lack of agreement on who should be labelled as having the condition. There is further debate as to what values should be used as a diagnostic tool for premenopausal women (the population of concern in this PhD thesis) as they have a far lower risk of fracture (Kanis 2005). It has been recommended by the International Society of Clinical Densitometry (ISCD) that a *Z-score* is used, as this is an age-matched standard deviation from populations of the same age (Lewiecki et al. 2008). There is a further argument that for premenopausal females a bone mineral density score should not be used alone in determining a diagnosis of osteoporosis. Instead, a history of low trauma fracture or a known secondary cause of osteoporosis should be used in conjunction with a low BMD score to determine the diagnosis. The ISCD

has made the recommendation that the term osteoporosis should not be used for premenopausal females and those young women with a Z score of <-2.0 should be categorized as merely having *low BMD* or a *BMD that sits below that expected for their age*. With the focus of this PhD research being the experience of living with a diagnosis of osteoporosis as a premenopausal woman, it is important to acknowledge how the experience of living with *low bone density* might compare to one of living with the diagnostic term *osteoporosis* due to the strong stereotype osteoporosis carries (as explored within Chapter Two of this thesis).

It is clear from the literature surrounding the use of the terms osteoporosis and osteoporotic, that the medical and academic community need to agree on whether osteoporosis is a static condition presenting as low bone density; low BMD with an associated increased risk of fracture; or whether to be truly *osteoporotic* the individual must be postmenopausal and present with a degenerative bone disorder - where the density of the bone is decreasing at a rate above that compared to the general population. Currently, it seems that the defining characteristics are not uniform and as a result, very different conditions are being grouped within literature. For epidemiology statistics, unless it is known precisely what criteria are being used to apply the term *osteoporosis* to an individual, there is potential for both over and underreporting of the condition.

iii. Premenopausal Osteoporosis

The prevalence of osteoporosis in younger women (20–44 years) is hard to establish due to the silent nature of the condition and the lack of BMD screening in this population. One study, using densitometry in a female Spanish population, found an incidence of premenopausal osteoporosis as 0.34%–0.17% (in the lumbar spine and femoral neck respectively) of their population (Diaz-Curiel et al. 2001). The estimated annual incidence within the United States is 0.4 cases per 100,000 (McLendon and Woodis 2014). Prevalence is hard to ascertain however, as there is no agreement on defining osteoporosis in premenopausal women and the fact that diagnosis should not be based on densitometric parameters (Martinez-Morillo 2011).

If the premenopausal osteoporosis is secondary osteoporosis (osteoporosis due to another factor), it is treated by addressing the primary cause whether that be medication prescribed for other conditions or modifying lifestyle factors (Cheng and Gupta 2013). The treatment for primary osteoporosis (postmenopausal) is the prescription of bisphosphonates that act to slow down bone turnover and so decelerate bone loss. This pharmacological therapy is currently not indicated for premenopausal females due to animal studies suggesting possible placental transfer and foetal skeletal development involvement along with the long-term effects in premenopausal women being unknown (Martinez-Morillo et al. 2012). Current drug trials for other medication are showing benefits in terms of improving bone density but the samples are small, and there is no evidence of a decreased incidence of fracture (Cohen 2017).

The significance of premenopausal / idiopathic osteoporosis, in relation to patient experience literature, is that the age of diagnosis contrasts so markedly with what Bury (1982, p.171) calls the "common cultural paradigm" for the condition. Osteoporosis is a condition with such a cultural paradigm. Its diagnosis has the potential to introduce the concept of premature ageing, initially proposed by Singer (1974), into the world of the patient, as osteoporosis is traditionally seen as a degenerative condition of old age.

In each of the three types of osteoporosis, the cycle of bone formation and resorption (that determines whether an adult reaches their full genetic potential of bone mineral density) was disrupted in some way. This genetic potential is defined as the skeletal size and mass that they should achieve presuming no restrictions on the supply of nutrients or any deficits in mechanical loading, below optimal, have been applied (Heaney et al. 2000). The skeletal growth spurt reported in teenager development contributes to 15% of their adult height with maximal height traditionally being achieved at the age of 16 in females and 17 in males (Chew and Clarke 2017). 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 and Clarke 2017).

Any interruption to this 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). The achievement of a person's full genetic potential for their skeleton is of paramount importance due to the natural and expected decrease in bone mineral density with age (Heaney 2000). Bone mass tracks throughout life with those at the high end of the bone mass distribution in pre-pubescence, still being at the upper end of the distribution following the pubescent growth spurt, and later in adult life (Chew and Clarke 2017). The condition of osteoporosis is therefore biographical. It is the representation of all that the body has been exposed to from the uterus to young adult (Heaney 2000). This biographical aetiology reinforces the chosen methodology for this present study.

iv. Summary

At present, there is no universal agreement on diagnostic criteria and indications for scanning for premenopausal osteoporosis. Accurate incidence data for premenopausal osteoporosis are hard to achieve due to the silent nature of the condition and the lack of screening of the premenopausal population, even when presenting with fractures and risk factors. For those with secondary premenopausal osteoporosis, the causative factors of the condition (such as specific medication use or physical inactivity) are addressed. For both secondary and idiopathic premenopausal osteoporosis, calcium and vitamin D supplementation alongside an increase in physical activity are indicated. Pharmacological interventions are not reported to reduce fracture risk, and in the case of bisphosphonates (the most common treatment for postmenopausal osteoporosis), the prescription could cause harm to premenopausal females and their unborn children.

No matter what definition or diagnostic criteria has been used, once a patient has been told they have osteoporosis, they enter an experience of living with the 'silent' condition, its threat of fragility fractures and the resultant implications of these fractures. The biomedical information associated with premenopausal osteoporosis

is limited. The experiences of those who have received a diagnosis of osteoporosis as a premenopausal female are noted by their absence.

1D. Illness Stories

Acknowledging the importance of working with patients and progressing health care provision from biomedical paternalism to an inclusive patient-centered approach, the Department of Health (DOH) produced a White Paper called Equity and Excellence: Liberating the NHS. This paper insisted that patients would be at the centre of the decision-making processes of the UK National Health Service (NHS) (DOH 2010) with a critical objective being an improvement of the patient experience. There has been a call within nursing research in particular to move the healthcare environment that has long been established through logic, linear and computer like analysis of patient data, to one that is interpretive and empathic (Lees 2011).

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). Studies in the 1960s and 1970s aimed to broaden Parson's (1951) conception of illness and the sick role (discussed more fully later in this section) through its application to chronic illness (Berkanovic 1972; Gallagher 1976, Gerson 1976; Gerhardt 1979). In the 1980s the diagnosis of a chronic illness was explored through the lens of the diagnosis being a disruptive event to the individual's life course expectations, through the concept of biographical disruption (Bury 1982). The diagnosis of chronic illness was shown by Bury (1982) to bring into the individual's present the reality of pain and suffering often only seen as distant events in one's future.

Burys' work on Biographical Disruption (1982) has been a feature of much of the sociological research into living with chronic illness. Utilising semi-structured interviews carried out with 25 women and 5 men who had been referred to a rheumatology clinic (the same medical speciality that views those with osteoporosis) his research had the aim of capturing the experiences of those people at "the

earliest possible point" (p.167) in their diagnostic journey. He outlined the diagnostic journey as being a continuum from an individual's increased attention to their bodily state and a decision to seek help; progressing to that individual reconfiguring their biography in order to process their arrival at their diagnosed state; and finally mobilising their resources in response to this newly disrupted state in order to face their new self, post diagnosis and with their new limitations. Bury's concept of biographical disruption has been applied to a number of illness conditions: perinatal loss (Davidson and Letherby 2014); Meniere's disease (Bell et al. 2016); rheumatic disease (Carranza 2017); and insomnia (Cheung et al. 2017) for example. Building on the work of Bury (1982), Williams (1984) stated that a life event such as a diagnosis of chronic illness has the potential to bring chaos to the individual's life and disrupt their life-course (Exley and Letherby 1990). This disruption means the individual has to reconstruct their narrative in order to "understand the illness in terms of past social experiences" (Williams 1984, p.179).

In the 1990s, Bury further developed his work to incorporate meaning:

> "In the first place, the 'meaning' of illness lies in its consequences for the individual […] Second, the meaning of the chronic illness may be seen in terms of its significance. By this I mean that different conditions carry with them different connotations and imagery" (Bury 1991, p.453).

This reference to imagery is of particular important to a condition such as premenopausal osteoporosis, a condition that generates particularly strong imagery of ageing and decline (Paier 1996). Following the disruption of the diagnosis event people have been shown to,

> "attempt to reconstitute and repair ruptures between their body, self and the world by linking up and interpreting different aspects of biography in order to realign present and past and self with society" (Williams 1984, p.197).

Since Williams (1984) personal illness stories have gained a key place in studies of illness experience (Charmaz 1983). Bury continued his work in the area of illness stories (narratives) by distinguishing between three types of illness narrative. "Contingent narratives" (Bury 2001, p.268) have to do with the beliefs and knowledge on the causation of the condition appearing in the person's life and its

immediate impact on the body, self and others. The "moral narrative" involves the evaluation of the links between the personal and the social (moral, religious considerations) (Bury 2001, p.274). Finally "core narratives" take into account the language used within the narrative to identify its form – epic/heroic, tragic, comic, romantic – with the concern that analysis of these narratives draw attention to form over meaning (Bury 2001, p.274).

The Department of Health made a concerted drive to acknowledge the importance of patient experiences to helping healthcare practitioners understand systems and practices from the patients' perspectives (Department of Health 2001). The most appropriate and relevant ways to assess the patient experience have been explored through comparing data collection methods such as surveys, patient stories and narrative methods (Lees 2011). Surveys have often been adopted to gain markers for patient satisfaction due to the ease of their deployment over large geographic areas, the fact that they are inexpensive and can gain feedback from large patient numbers (Monsen & Van Horn 2008). Patient accounts, however, allow the practitioner to place themselves in the position of the patients and be receptive to the realities presented concerning the patient's feelings and interpretations of their experiences. These accounts have the potential to influence change in health service delivery (House of Commons Health Committee 2007). Patient narratives provide chronologically detailed stories of health and illness (McCance et al. 2001). They reflect the reality of the individual's experiences (Lees 2011).

> "Humans are storytelling organisms who, individually and collectively, lead storied lives. Thus the study of narrative is the study of the ways human's experience the world" (Connelly and Clandinin 1990, p.2).

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 and Douglas 2013). Personal accounts are the stories through which a person can position themselves and their experience of their illness or condition, within time (Sparkes and Smith 2014). Research using illness stories (narratives) have covered a broad range of topics including chronic fatigue (Bulow et al 2013); spinal cord injury (Sparkes and Smith

2003); asthma (Owton 2013); HIV (Ware 2013); illness in the homeless (Hakanson and Ohlen 2016); and endometriosis (de Souza Sao Bento et al. 2017).

According to Frank (1995), there are three types of illness story; the restitution narrative, the chaos narrative and the quest narrative. While Frank accepts that there is a risk in creating a unifying view that forces patient stories into one of three categories, he proposes that this categorisation allows closer attention to be paid to the accounts that those with illness tell and aids reception of those stories and their "narrative threads" (Frank 1995, p.76). He also acknowledges however that no actual story adheres exclusively to one narrative type and combines all three with each "perpetually interrupting the other two" (Frank 1995, p.76).

The plot of the restitution narrative is one dominant in those who are recently ill but not chronically ill. The basic storyline is "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" (Frank 1995, p.77). Restitution narratives reflect a natural desire to get well and stay well. It is also a learnt story that is socially acceptable in that it models how illness should be told. Institutional medicine can use these stories to tell their preferred version of illness events, pushing the time spent living through illness into a minor role and focusing on the successful life post-illness. The restitution narrative is congruent with Parsons' sick role concept (1951) in which illness has a limited duration and recovery is certain (hence this narrative type not applying to those with chronic illness). Within Parsons' work illness is not regarded as the sick person's fault, only as a result of some form of excess. As a sick person, one is exempt from normal daily roles and responsibilities at home and work – an exemption that is both expected by the ill person and offered by those around them. To control these elements of the sick role the ill person must:

> "place himself under the authority of a recognised professional' and 'comply with doctors' orders" (Frank 1995, p.81).

Wellness is therefore achieved not through any action by the patient but the expertise of others. There are limitations to this approach as the restitution narrative cannot be applied in the case of chronic illness or terminal illness as the

previous state of wellness can never be restored. Smith and Sparkes (2003) and Sparkes and Smith (2011) found that even amongst those with severe permanent disability participants still chose to tell a restitution-based narrative as it indicated the hope for restitution that was key to their experience.

The chaos narrative is the opposite of restitution; the patient and their life will not get any better. The story lacks any order and is told as the patient experiences life, without sequence or discernible causality. This disorder means the story is often difficult to hear. While restitution stories are deemed to be reassuring, chaos stories produce anxiety as they reveal vulnerability and futility. The telling of a chaos narrative requires distance from the life event to allow reflection.

> "Lived chaos makes reflection and consequently storytelling, impossible"
>
> (Frank 1995, p.98).

Lived chaos means that chaos narratives cannot be told, but only lived. This chaos of immersed living through an event is evident in Bruner's "life as experienced" (Bruner 1984, p.7). The commentary of the individual's daily struggle is within time, without reflection or distance and with the bottomless depths of "and then and then and then" as the "chaos encompasses all areas of that individual's world" (Frank 1995, p.99).

Within chaos narrative, no one is in control. Frank proposes that what is needed in both clinical work and more generally, is an enhanced tolerance for chaos as part of the life story. Clinicians have a tendency to try to pull someone out of their chaos as it represents a critique to the modernist assumptions of clinical work, but Frank states we must accept that chaos is part of a process of living and that life is sometimes "horrible" (Frank 1995, p.112).

Within the quest narrative suffering is met head-on, illness is accepted, and the patient seeks to use it as a journey to achieve a quest. The overriding belief of the quest narrative is the ill person's belief that "something good is to be gained through

the experience" (Frank 1995, p.115). The teller of the quest narrative is one looking for purpose and meaning in their lives as a result of their illness and looks to share this journey to inspire others. The quest narrative empowers the ill person to be the storytellers of their own story. In the restitution narrative, the health practitioner or intervention is the focus of success. Within the chaos narrative, the story belongs to the ill person, yet their suffering is too great for the story of the self to be told. Quest narratives speak from the ill person's perspective and hold chaos at bay, and so if chaos narratives are Bruner's life as experienced, the quest narrative has similarities to the "life as told" (Bruner 1984, p.7).

i. Illness Story Methodology

Osteoporosis is a condition that has its roots in the skeletal development of adolescence. To advance knowledge and theory in the field of premenopausal osteoporosis, a methodology has been chosen to take into account the answering of the research question and to capture this biographical natural-history of the osteoporosis. With personal experience of the condition, the research question was aligned to a researcher-as-participant methodology. Researcher-as-participant methodologies have been explored, including autoethnography, autophenomenography and autobiography. Through an autobiographical approach influenced by the work of Denzin (1989), Erben (1998), Johnstone (1999), Exley and Letherby (2001) a reflective exploration of the personal experience has, at its focus, the examination of the meaning of subjectively perceived human lived experience and the physical, social, political, cultural, moral and historical context of that experience (Johnstone 1999). The records of a life as lived, as experienced and as recorded (Denzin 1989) renders an account of the experience of living with premenopausal osteoporosis that advances shareable understanding of common human experiences.

Using this methodology, readers should be able to find something in common with the account given. The aim of seeking this commonality is that readers, in turn, may be able to expand their horizons of insight into,

> "depth of understanding about their own lived experiences and the meanings they have attributed to them" (Johnstone 1999, p.25).

In order to find this resonance the readers of illness narratives must "employ imagination" (Erben 1998, p9) and use it to,

> "aid recognition of significant moments in the data to relate these to each other and to the overall lives of the subjects under study" Erben 1998, p.10).

The process of methodological exploration, decision-making, and the importance of resonance is reported fully in Chapter Three.

1E. Delimitations

The focus of this research is on the experience of living as a young, active premenopausal female, with the condition of osteoporosis. With personal experience of the condition, the researcher is the participant in this study. With in-time experiences being recorded through personal diary, long before the research study was conceived, this present study will focus on the period of time that incorporated both the diagnostic journey and the two years following diagnosis. There are currently no studies that have explored this condition, in this way.

There is currently no screening programme for young women in the United Kingdom to identify premenopausal osteoporosis. As a result many women may have osteoporosis or low bone density but have not yet been diagnosed. Whilst common risk factors for premenopausal osteoporosis have been a topic within the literature on the condition and have been discussed within this introductory chapter, very few women receive follow up scanning should they present with such risk factors. We know that premenopausal osteoporosis is an ever growing public health issue (as is postmenopausal osteoporosis) yet the lack of screening makes research populations difficult to identify. Further participants have not been included within this present study, partly due to the issues in identification of those with the condition, but also due to the differences between retrospective and current data collection methods. This present research focuses on the experience of living with premenopausal

osteoporosis as it was experienced in-time rather than asking others to recall their experiences after the event. It is the aim of this research to present rich descriptions of the experience of living with osteoporosis to enable imagination and resonance, to support the reader in understanding the implications of the diagnosis for a young woman.

1F. Structure of the Thesis

This thesis will address the need for research in the field of premenopausal patient experience in the following way:

Chapter Two: Review of Literature

The systematic approach to the review of literature explores the currently available research on patients' experiences of living with osteoporosis. This review helped develop an understanding of the components of experience as reported by traditional patients of the condition. The literature on the experience of the only other non-traditional group, males with osteoporosis, is also explored to gain an understanding of the unique elements this demographic experience.

Chapter Three: Methodology

To provide substantial justification for the method and methodology chosen this chapter outlines the paradigmatic assumptions that have been applied to this work. A discussion of potential approaches and methodologies is presented. A more in-depth analysis of the final methodology concerning its history and development added to the justification for it being chosen for this study. The selected process of autobiography is articulated to demonstrate the process through which the experience of living with a condition has been developed into an academic study of a "life told" (Bruner 1984, p.7).

Chapter Four: Main Findings

Chapter Four presents the data from which the discussion and analysis are based. The chapter is presented in two parts. Part One tells the story of "life as experienced" (Bruner 1984, p.7) from the start of the diagnostic investigations until two years post diagnosis (two years). Part Two then presents the reflective topical autobiographical accounts (Johnstone 1999) through its presentation of themes and distinctive qualities of the experience of living with osteoporosis as a premenopausal female.

Chapter Five: Discussion

This chapter takes each of the reflective accounts in Chapter Four and explores them with the broader literature on chronic illness, to place the experience presented within a broader context.

Chapter Six: Conclusion

Findings are summarised here, and the aim of the research is addressed. The limitations of the study are acknowledged and recommendations for future research are provided. A summary of the dissemination of findings to date is provided.

1G. Chapter Summary

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 is no different. The focus of research to date has 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 and 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) (Heaney et al. 2000;

Bonner et al. 2003; Guadalupe-Grau et al. 2009; Ilinca et al. 2010; Banu 2011; Ebeling 2011; Lukert et al. 2011) and to a lesser extent public awareness of the condition (Tanna 2009; Chang et al. 2010). There is a lack of literature on the patient experience for those with osteoporosis and the research on premenopausal osteoporosis patient experiences seems absent altogether. The researcher has personal experience of their diagnostic journey and the subsequent process of living with premenopausal osteoporosis. A researcher-as-participant methodology has been chosen to add new knowledge to the field of osteoporosis and a theoretical contribution to patient experience literature.

This introductory chapter has laid the foundations for this thesis through the introduction of both personal and academic context, the research question and a brief description and justification of the methodology. The outline of the thesis has been presented and can now proceed with a detailed description of the research, beginning with a thorough exploratory examination of the literature on experiences of living with osteoporosis in the following chapter.

CHAPTER 2: REVIEW OF LITERATURE

2A. Chapter Introduction

This chapter presents the systematic approach that was taken to explore all relevant literature on the patient experience of living with osteoporosis. With objective literature searches such as this, the application of predetermined inclusion and exclusion criteria and the extraction and synthesis of findings from these papers enables the review to provide a synthesis of individual studies. This synthesis results in the understanding of complex and multifaceted health experiences and health care practices to provide a collective voice from a broad experiential perspective (Disler et al. 2014).

There is continued discussion as to the more appropriate terminology to use to describe those who are part of a medically led health care journey. The term *patient* had been out of favour, with a preference towards *service user*, *expert by experience, person* and *individual with* (McLaughlin 2009). Each of these terms serves to remove the individual from a submissive role in biomedical paternalism and place them as equals in their health care journey. Recently however there has been a move back to the term *patient* as it is one that most people understand (Christmas and Sweeney 2016). Within this discussion those with a condition are being termed patient not to reinforce hegemony but to ensure clarity for the reader.

i. Search Strategy

A computerised literature search was completed using the mySearch database (Bournemouth University) that included: CINAHL Complete, MEDLINE complete, PsycINFO, ScienceDirect, British Library EThOS, SportsDiscus, SocINDEX, Environment Complete, SciELO, Education Source, PsycARTICLES, Business Source Complete and Hospitality & Tourism Complete. The strategy searched publications from January 1st 1996 to October 5th 2017 to ensure patient experiences were set within the context of current national health care processes and practices (in relation to the current NHS provision for osteoporosis). The year of 1996 was chosen as this was

the year before Governmental change in the United Kingdom (from Conservative to Labour), and the resultant reviews of the NHS and patient care, leading to the production of the policy paper, *High quality care for all: NHS Next Stage Review* (Darzi 2008). Searches were limited to peer reviewed, English language, academic journals and PhD theses. The search terms used to identify words in the title or abstracts were:

life experience OR everyday liv* OR everyday life OR liv* experience* OR liv*

AND adjust* OR adaptat* OR transition*

AND osteoporosis OR pre*menopausal osteoporosis

AND qualitative

Studies were included if they addressed living with osteoporosis from the patients' perspective; if those patients were over the age of 18, literature reviews, qualitative, quantitative and mixed methodologies were included; grey literature such as books, and theses were also included. Studies were excluded if the lived experience was from a family or professional perspective; self-management studies (as that is a different phenomenon for investigation outside of this research); articles that identified a single factor for investigation that might influence the patients' experiences for example depression, fatigue, psychological profiling etc; and where the patients' were experiencing multiple severe conditions rather than one single chronic condition.

ii. Search Results

A total of 392 articles were generated in this search. Having screened each article by title and abstract to assess inclusion eligibility 38 articles remained. The removal of duplicates and screening of full texts for exclusion criteria resulted in 13 articles being eligible for inclusion exploring the experiences of 291 participants with osteoporosis (225 female and 66 male). After full text reading the following studies were excluded from the analysis:

Research Author	**Reason for exclusion from full text analysis**
Quantock & Beynon (1997)	A focus on service provision
Richardson et al. (2002); Sale et al. (2011); Sale et al. (2015); Beaton et al. (2012)	A focus on diagnostic tools and screening programmes, rather than patient experience
Wilkins (2001a)	A focus on managing ageing and multiple co-morbidities
Wilkins (2001b)	A specific focus on self-concept
French et al. (2005); Papaioannou et al. (2007); Mazor et al. (2010); Inversen et al. (2011); Sale et al. (2011); Salter et al. (2014)	A focus on medication use
Qvist et al. (2011)	An analysis of specific intervention findings
Sale et al. (2014a)	A focus on individuals with a T-score of -1.0 rather than -2.5 as a confirmed diagnosis of osteoporosis
Sale et al (2014b)	A focus on consumer behaviour of those with osteoporosis rather than patient experience
Clarke et al. (2005)	Emphasis on decision making
Jachna & Forbes-Thompson (2005)	Focus on health beliefs
Giangregorio et al. (2009)	No confirmed diagnosis of osteoporosis
Hallrup et al. (2009)	An explicit focus on those aged between 75-86 with the emphasis being on logistical issues in reaching appointments.
Svensson et al (2016)	A focus on older women's experiences of current vertebral fractures.

Table 2: Studies excluded from analysis following full text reading.

Of the 13 papers included for full text analysis, only two featured individuals of premenopausal age (McKenna and Ludwig 2008; De-Souza et al. 2010) although neither states how many participants were in this demographic. There was no indication within the qualitative analysis of the experiences of these individuals, the age of the participants for whom direct quotes were utilised or whether the younger participants experienced any particular issues or concerns in relation to the research topic of self-managing osteoporosis. The remainder of the studies included in the review featured participants of postmenopausal age only. Included papers are listed

in the table that follows. At this point, the justification for this present research was reinforced due to the paucity of literature for the premenopausal diagnostic group.

Authors	Age reported	Country	Focus	Gender	Data collection analysis
Paier (1996)	58-86	USA	Spectre of the crone: the experience of vertebral fracture	5 women	Semi-structured interviews, Colaizzi's analysis (phenomenology)
Roberto & Reynolds (2001)	53–89	USA	The meaning of osteoporosis in the lives of rural older women	21 women	4 focus groups, thematic analysis
McKenna & Ludwig (2008)	43–82	UK	Osteoporotic Caucasian and south Asian women	21 women	Semi-structured interviews, phenomenology
de-Souza et al. (2010)	36–79	Brazil	Self-managing osteoporosis treatment for wellbeing recovery mediated by the (in)visibility of the disease signs	12 (11 women)	Non-structured interviews, grounded theory
Hallberg (2010)	68–84	Sweden	A striving for independence: a qualitative study of women living with vertebral fracture	10 women	Semi-structured interviews, content analysis
Nielsen et al. (2011)	51–82	Denmark	Men's experiences of living with osteoporosis	16 men	4 focus groups, phenomenology
Solimeo et al. (2011)	70.36 (53–86)	USA	Older men's explanatory model for osteoporosis	23 men	Semi-structured interviews, thematic analysis
Weston et al. (2011)	68–79	UK	The invisible disease: making sense of an osteoporosis diagnosis in older age	10 women	Semi-structured interviews, phenomenology
Besser et al. (2012)	69 (SD 10.1)	UK	How do osteoporosis patients perceive their illness and treatment? Implications for clinical practice	14 women	Semi-structured interviews, drawings, thematic analysis
Sale et al. (2012)	65–88	Canada	Patients reject the concept of fragility fracture – a new understanding based on fracture patients' communication	30 (21 women)	Semi-structured interviews, descriptive phenomenology
Nielsen et al. (2013)	50–84	Denmark & UK	Handling knowledge on osteoporosis	26 (20 women)	Semi-structured interviews, phenomenology
Hansen et al. (2014)	65–79	Denmark	Women's experiences of their osteoporosis diagnosis at the time of diagnosis and 6 months later	15 women	Open interviews, phenomenology
Barker et al. (2016)	-	UK	A qualitative systematic review of patients experience of osteoporosis	34 studies, 773 participants (83 men)	Metaethnography

Table 3: A summary of papers included for full text analysis

iii. Synthesis of Findings

In order to develop an over-arching understanding of the key areas of patients' experiences of living with osteoporosis, each of the papers was read in full and the findings sections were screened line by line for free codes. These were documented for all papers and synthesised to form hierarchal descriptive themes (Thomas and Harden 2008). At this point it is important to highlight that it was impossible to differentiate within the papers which comments (codes) were made from those who were premenopausal and those who were postmenopausal as no ages were presented with any direct quotes or data reporting. The synthesis of the literature review resulted in the following themes and subthemes of experience:

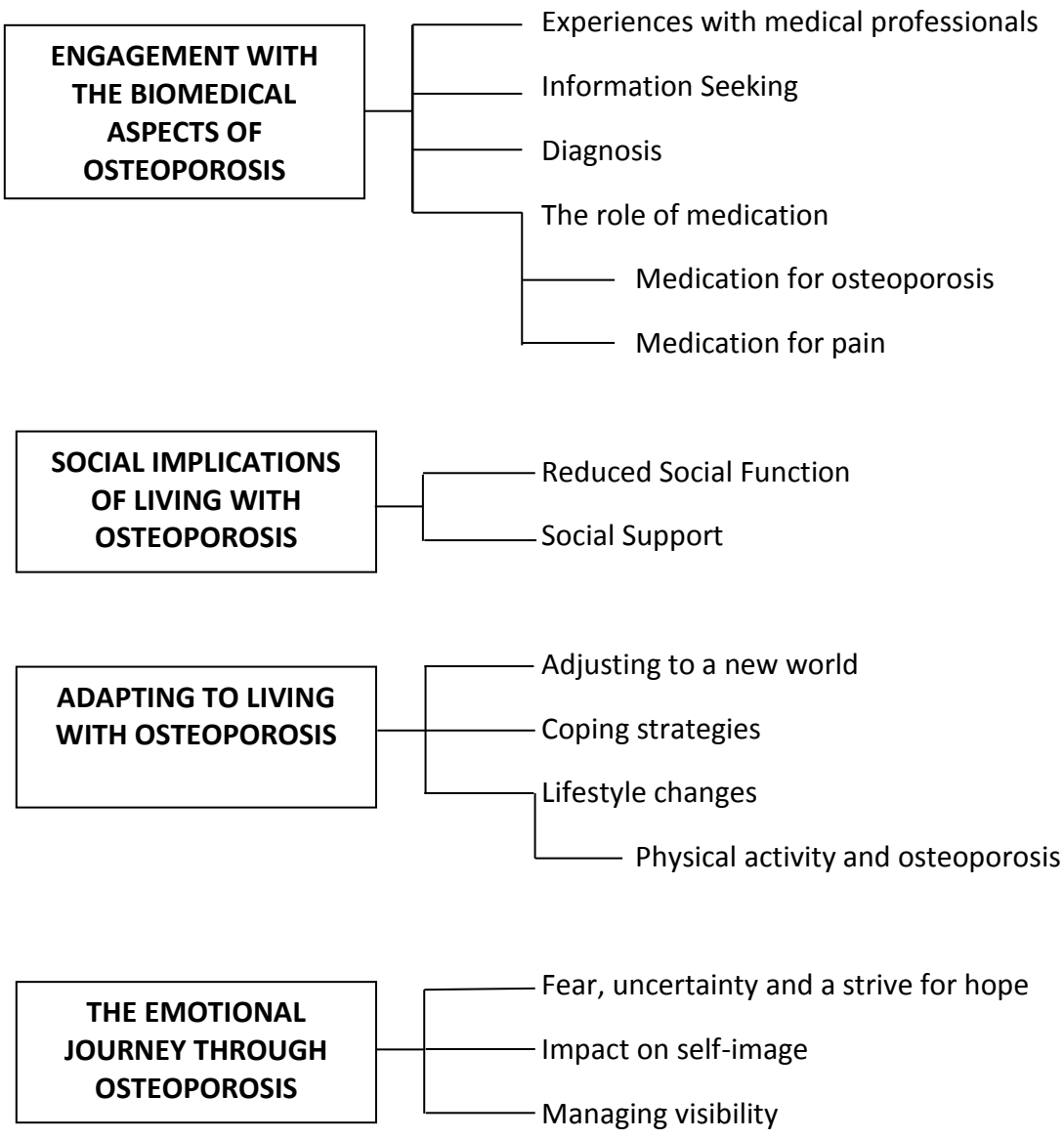


Figure 3: A thematic synthesis of research exploring the patient experience of osteoporosis

2B. Engagement with the Biomedical Aspects of Osteoporosis

Through reviewing the literature relating specifically to the experiences of those with a diagnosis of osteoporosis it can be seen that a number of areas for discussion are evident under the heading of Engagement with the Biomedical Aspects of Osteoporosis. These include Experiences with medical professionals; Information Seeking; Diagnosis; and The Role of Medication.

i. Experiences with Medical Professionals

Individuals either undergoing investigation for, or receiving a diagnosis of osteoporosis have according to the literature inconsistent satisfaction with the medical profession (Roberto and Reynolds 2001; McKenna and Ludwig 2008; Hallberg 2010; Solimeo et al. 2011; Weston et al 2011; Besser et al. 2012; Neilsen et al 2013; Hansen et al 2014). For some, who had previously had a good, longstanding relationship with their General Practitioner (GP), there was a feeling that the practitioner was caring, providing support and answering questions fully. Trust, based on the GP successfully treating previous health issues provided reassurance, with these GPs being described as skilled, reassuring, caring and as the expert (McKenna and Ludwig 2008; Hallberg 2010; Weston et al. 2011). Individuals reported wanting to be taken seriously and felt their GP demonstrated this if they showed an awareness of an increased risk of osteoporosis due to previous illness etc. and were proactive in following up their concerns through scanning (Hansen et al. 2014). When making an effort to listen, understand and provide support and treatment options, women felt they were treated with understanding and respect. When they receive answers about fractures, treatment and help with exercises, they also had positive experiences (Hallberg 2010) although it is beyond the scope of these studies to identify if the information received by these individuals was the most recent evidence and best practice, or not.

Not being treated with understanding or knowledge as well as being ignored by medical professionals was also commonly experienced (McKenna and Ludwig 2008; Hallberg 2010; Besser 2012). Lack of time during consultation, poor communication, lack of continuity of care and lack of knowledge in relation to osteoporosis were all

reported in relation to individual's experiences of the medical profession during their osteoporosis journey (McKenna and Ludwig 2008; Hallberg 2010; Besser 2012). For younger women (aged 43-50) in particular, there was a feeling of dissatisfaction with their care (although this dissatisfaction is evident at all ages (de-Souza et al. 2010). Individuals reported wanting more information about their condition that was not available through their GP. A feeling of knowing more than the GP can quickly develop (McKenna and Ludwig 2008). There was a lack of confidence, and lack of certainty in the GP as the practitioner closed down information-seeking conversations. Younger individuals felt they must find their own information, push the GP to answer questions, and lead all conversations from this point of self-learning in order to ask the practitioner the right sorts of questions that would get a response (McKenna and Ludwig 2008).

The doctor-patient relationship was also shown to affect adherence to any interventions (Besser et al. 2012). The main help received from professionals was regarding medication use and scans although most believed this treatment was not adequate (Hallberg 2010). Professional guidance in relation to physical activities, involvement of relatives, the availability of healthcare professionals to listen to the individuals and their health issues and answer their questions are important in coming to terms with osteoporosis (Neilsen et al. 2013).

ii. Information Seeking

The perceived lack of information given by the medical profession with regard to an individual's diagnosis of osteoporosis and its impact on their life resulted in a process of personal information seeking by that individual (Paier 1996; Robert and Reynolds 2001; McKenna and Ludwig 2008; Weston et al. 2011; Hansen et al. 2014). This information seeking came from a number of sources such as television, the internet, support groups, women's magazines and the National Osteoporosis Society in the United Kingdom or International Osteoporosis Federation overseas (Robert and Reynolds 2001; McKenna and Ludwig 2008; Neilsen et al. 2013). With information seeking being seen by Paier (1996) as a part of self-taught resilience, the information found was both frightening and enlightening to individuals (Paier 1996). Ultimately

the information seeking process empowered individuals by providing the information required for them to take written lists of specific questions to their doctors and consultants appointments (McKenna and Ludwig 2008).

iv. Diagnosis

The process of diagnosis was seen to be a long and drawn out one (Roberto 2001; McKenna and Ludwig 2008; Hansen et al. 2014). Some individuals were recommended to have DEXA scans to determine their bone mineral density after presenting with a decrease in height over time (Roberto 2001) whilst others were recommended for scanning following a fracture at postmenopausal age. Receiving the diagnosis of osteoporosis, in some cases, took many years (Hansen et al. 2014) with scan results only being part of the diagnostic journey. Following a positive diagnosis, many participants reported not knowing how severe their osteoporosis was, just that they had it, and that it was hard to process a diagnosis that had no pain attached to it (Weston et al. 2011; Besser et al. 2012). The invisibility of the condition makes it hard for many individuals to see themselves as being unwell (Hansen et al. 2014) having been well and active for much of their lives (Roberto 2001). Even those who have fractured already would attribute that fracture to another cause rather than low bone density (Besser et al. 2012).

Older patients reported the diagnosis having less of an impact at their age than if it was when they were younger, as they did not really see the implications of having low BMD. The diagnosis was only really an issue for them if the condition ever affected their mobility or independence (Sale et al. 2013). For those who had experienced fracture there was difficulty attributing the fracture to osteoporosis (Roberto et al. 2001) with many providing a strong rationale for the cause of the fracture not being due to 'fragility' but more likely a freak accident (Besser et al. 2012; Sale et al. 2012). Where individuals had trust in their medical team there was an immediate acceptance of the diagnosis whilst others refused to accept the diagnosis as for them it was a sign of getting old, and this was depressing for them (Hansen et al. 2014).

v. The Role of Medication

Medication for Osteoporosis

The complexities of using medication was very visible within studies exploring the patient experience of osteoporosis, with many participants taking time to decide if they wished to take the medication due to the potential side effects (Solimeo et al. 2011; Besser et al. 2012; Hansen et al. 2014). Younger women especially wanted strategies and interventions other than medication (McKenna & Ludwig 2008) yet medication seemed to be the first course of action on receipt of the diagnosis (McKenna & Ludwig 2008; Weston et al. 2011; Nielsen et al. 2013; Hansen et al. 2014). Some individuals gained a feeling of reassurance and safety through taking the medication as it was interpreted as a solution to the bone loss (Weston et al. 2011). They did not ask the GP how the medication worked but just assumed that because they had been prescribed it, it would stop the condition progressing (Weston et al. 2011; Hansen et al. 2014). Feedback from follow up scans helped them realise the medicine was beneficial and working and so reinforced their motivation to take it (Besser et al. 2012). Hopes of being able to stay active were similarly used as motivation for medication adherence (Nielsen et al. 2013). If the medication, however, made the individual feel unwell and they were not experiencing issues with their osteoporosis they would abstain from treatment to restore a feeling of wellbeing until there was another manifestation of the condition, when they would continue the treatment once more (de-Souza et al. 2010).

For those individuals not wanting to immediately take medication some wanted regular monitoring and would start their prescription if their condition started to worsen (Nielsen et al. 2013). Their internal conflict over whether to take the medication or not was a dominant feature in their lives (Besser et al. 2012; Nielsen et al. 2013). Concerns over side effects, addiction, a dislike of pharmaceutical companies, media reports of links between bisphosphonates and cancers, all contributed to a reticence in starting medication without trying physical activity and other lifestyle interventions initially (Roberto and Reynolds 2001; Besser et al. 2012; Nielsen et al. 2013; Hansen et al. 2014). The decision to take medication was easier for those who had *bigger* issues in their lives that they were processing, such as

bereavements or co-morbidities (Hansen et al. 2014). Some presented with a fear of stopping the medication after their prescribed length of time (Nielsen et al. 2013), and there was confusion over the medication only being indicated for five years when their condition is chronic and incurable (Besser et al. 2012). Subjective reasoning for either taking or not taking medication was connected more to feelings of guilt or fear rather than objective conditions such as side effects (Nielsen et al. 2013). The medication given to those with postmenopausal osteoporosis is not indicated for premenopausal women (Martinez-Morillo et al. 2012). Nothing is reported in the literature in this review as to the advice this population of women in particular have been given regarding medication.

Medication for pain

With the physical presentation of osteoporosis being fracture and pain, pain medication may feature heavily in the lives of those with present fractures or who have long term effects from previous fractures. Fractures themselves have been reported as being both physically and emotionally traumatic (Sale et al. 2012). There is a marked disconnect between the medical language attributed to osteoporotic fracture occurrences for example 'low trauma' and 'fragility,' when compared to the language used by the individuals sustaining the fracture. Here forceful, action-oriented words such as banging, crashing, flying and landing onto hard surfaces are used (Sale et al. 2012).

Primary pain is attributed to fracture sites, if known, with a continuing pain or threat of pain acting as a marker to patients as to how serious the condition is (Weston et al. 2011). Vertebral fracture pain, in particular, has been described as a totally unnatural life dominating and debilitating pain with the pain and subsequent suffering, severely affecting the quality of life of those individuals (McKenna & Ludwig 2008; Hallberg 2010). These fractures have a continuing influence on life with initial pain from the fracture, continuing pain due to spinal deformity caused by the fracture and a threat of pain and further fractures in the future (Paier 1996).

Where pain cannot be attributed to a known cause it affects the cognitive processing for the individual for both their condition and their treatment. The incongruity of the pain of atraumatic vertebral fractures leads to an uncertainty in the correct diagnosis (Paier 1996). Activities that appear to cause most pain are prolonged standing, getting in and out of cars, sleeping or lying down for long periods (Paier 1996; Roberto and Reynolds 2001; McKenna & Ludwig 2008). The negative impact of pain on sleeping increases fatigue and decreases one's quality of life markedly (Paier 1996; Roberto and Reynolds 2001; McKenna and Ludwig 2008). For those with actively painful representations for their osteoporosis, for example, spinal curvature or fracture, there is a need to take pain medication. For these individuals there is an active balance between taking the pain medication and managing the side effects; between easing the pain and feeling 'zoned out' (Paier et al. 1996; Hallberg 2010). For those for whom pain killer use is long term, there is a fear of dependence and addiction to this medication (Paier 1996; Hallberg 2010). For some with a diagnosis of osteoporosis for whom fracture and pain are not yet evident it is hard to understand a diagnosis that has no symptoms or pain attached to it (Weston et al. 2011). There is no specific mention within the literature included in this review on the known side effects of pain medication on bone density, for example, non-steroidal anti-inflammatory drugs (NSAIDs) (and to a lesser extent opioids) have been shown to be linked to more fractures than expected in a ten year study of 2,016 perimenopausal women in the Danish Osteoporosis Prevention Study (Vestergaard et al. 2012).

2c. Social Implications of Living with Osteoporosis

i. Reduced Social Function

Reduced social functioning as a result of osteoporosis was primarily due to pain. This pain was itself a primary direct cause of reduced activity due to an inability to complete long road trips, pain when sitting for long periods or pain when trying to sit down or stand up (Paier 1996; Roberto and Reynolds 2001; Hallberg 2010; Nielsen et al. 2013). Secondary causes associated with pain were the effects of pain medication causing a feeling of distance from ones surroundings, wanting to avoid the feelings

of others being uncomfortable with the pain being suffered, avoidance of changes in family and friends as one is always deemed to be in pain (McKenna & Ludwig 2008). The reduction in ability to perform daily family roles caused upset with some expressing sadness over their inability to now look after their grandchildren, as they could not bend down to play with them (Roberto and Reynolds 2001).

Being able to leave the house when wanting to was key to a feeling of independence and 'normality,' yet some were now scared to go out on their own (Hallberg 2010; Nielsen et al. 2013). When weighing up whether to take part in an activity the perceived risk of fracture was always a factor, for example, when walking in bad weather (Paier 1996). Knowing ones' limitations and always being ready for something to happen were seen as methods of risk management (Paier 1996; Roberto and Reynolds 2001) with decision making as to which activities to continue, modify or restrict being associated with the relative risk of fracture that the activity carried (Paier 1996; Roberto and Reynolds 2010; Hallberg 2010).

The ability to manage everyday tasks and perform everyday activities was important for maintaining quality of life, but individuals with osteoporosis reported being more aware of the activities in their daily lives and take extra precautions against falling (Hallberg 2010; Weston et al. 2011; Nielsen et al. 2013; Sale 2012). There was an element of fear of everyday activities such as changing bedding, in those with a history of spinal fractures and they did not know what force would be needed for them to fracture once more (Nielsen et al. 2013).

ii. Social Support

Social support was evident in two forms; the support offered by family and that offered by others with the condition. For some, osteoporosis support groups were a thoroughly enjoyable and beneficial experience, providing an opportunity to spend time around others in a similar situation to themselves (Nielsen et al. 2013). For others, they did not feel relevant, were rife with one-up-manship and were a situation in which there was the potential for them to come face to face with someone in a worse condition than themselves. They did not want to do this as it

left them feeling worse about their situation and more fearful of the future, rather than feeling supported (Nielsen et al. 2013). The group dynamics determined how helpful these sessions were in that patients felt they needed to be in groups of similar situations, dealing with similar problems (Nielsen et al. 2013).

Within the family unit, women with osteoporosis struggled with being unable to fulfil their role as family care-giver. Worse still was if these women lost their care-giver role and became the one needing the care (Roberto and Reynolds 2001). Husbands to women with osteoporosis could be overly worried about their wives and want to go everywhere with them (Roberto and Reynolds 2001) and some women acted more disabled than they were so as not to offend well-meaning family members (Roberto and Reynolds 2001). Practical support from husbands and the wider family was seen as their helping with household chores and providing emotional support. Contact with family gives strength and energy (McKenna and Ludwig 2008; Hallberg 2010; Besser 2012). Changes in attitude of family and friends were a fear for many with osteoporosis, with pain presentations making individuals fearful of becoming the person always in pain. That pain, however, often made others feel uncomfortable and left the individual feeling that they were being treated as if contagious (Paier 1996). Social occasions were avoided for fear of not being able to make the car journey, get up and down stairs or sit comfortably (Hallberg 2010).

2D. Adapting to Living with Osteoporosis

i. Adjusting to a New World

Most individuals with osteoporosis demonstrated a strong desire to feel they were making attempts to control their condition. This included adopting lifestyle modifications such as taking up exercise, changing their diet and making sure they were wearing footwear that might reduce their risk of falling (Sale et al. 2013). Others showed a lack of awareness of the power they had to affect their condition through these changes (Besser et al. 2012). Coping strategies adopted by those with osteoporosis appeared to start with trying to attribute and process the cause of their condition, with many patients being able to list the risk factors for osteoporosis but

not recognise any of them in their life histories (Besser et al. 2012) or reconcile how they could have prevented their condition from developing in the first place (Hallberg 2010; Solimeo et al. 2011; Sale et al. 2012).

ii. Coping Strategies

Whilst some refused to think about their condition as they found it depressing (Roberto and Reynolds 2001; Hansen et al. 2014) or they wished to ignore it to lessen its impact on their life (Roberto and Reynolds 2001; Sale et al. 2012; Hansen et al. 2014) others adopted a more comparative optimistic outlook by thinking that it could be worse and simply avoiding activities that might exacerbate the condition (Hallberg 2010; Weston et al. 2011; Nielsen et al. 2013). For many, the decision was that thinking about the diagnosis only had negative consequences and such would be avoided (Weston et al. 2011). Many women had been through tough aspects of their lives such as bereavements, and so felt dwelling on their bone condition would be out of proportion with what they had already experienced (Weston et al. 2011). Anxiety over the future was managed by telling themselves that if it gets worse, it will be in ten years when they are in their 80s (Nielsen et al. 2013). This fatalism was evident in McKenna and Ludwig (2008) where participants reported that they could not build bone so late in life so they might as well get on with living in the here and now. There was a sense of inevitability that ill health such as high cholesterol, hypertension, and osteoporosis were just an expected part of ageing (Weston et al. 2011).

Ultimately the personal ability to deal with knowledge about the consequences of osteoporosis did not appear to relate to the seriousness of the condition but more related to the individual's network, their relation to relatives, and their personal resources and view of life in general (Nielsen et al. 2013).

iii. Lifestyle Changes

Lifestyle changes were made by the majority of individuals following a diagnosis of osteoporosis. These were based on an acceptance of restrictions and a desire to maintain independent living, through reducing the risk of falling (and the resultant

fractures) (Paier 1996; McKenna and Ludwig 2008; Hallberg 2010; Besser et al. 2012). These changes ranged from moving to a bungalow following falls down stairs (Roberto and Reynolds 2001) to not carrying heavy bags or reaching into high cupboards (McKenna and Ludwig 2008; Hallberg 2010). One study in particular, however (Weston et al. 2011) found that its participants did not realise that anything other than medication could impact positively on their bone health. One of the main changes was, the introduction of, or, increased determination to, carry out physical activity (Paier 1996; McKenna and Ludwig 2008; Hallberg 2010; Nielsen et al. 2013; Sale et al. 2012).

iv. Physical Activity and Osteoporosis

Physical activity as an intervention for the treatment of osteoporosis seemed poorly endorsed by medical professionals (Paier 1996; McKenna & Ludwig 2008). When it was spoken of, individuals felt that the information was inconsistent and that general practitioners lacked specificity when talking about the bone building effects of physical activity (Hallberg 2010). Individuals were afraid of doing something wrong, or trying an exercise that may be harmful, so felt they needed support to help educate them in what they could and could not safely do (Hallberg 2010). Motivation to use physical activity as an intervention was driven by fear or having to leave one's home or become dependent on others (Hallberg 2010) and recognition that improved strength and balance was making daily household tasks easier to manage (Hallberg 2010). A desire to get back to a fully active lifestyle was linked to hope that a return to normality could be achieved (Nielsen et al. 2012). Physical activities adopted by those with a diagnosis of osteoporosis included walking, tai chi and lifting light weights (Sale et al. 2012). Some reported a fear of continuing to ride a bike in case they fell off and ceasing skiing and skating as they were such high-risk activities (Sale et al. 2012).

2E. The Emotional Journey through Osteoporosis

i. Fear, Uncertainty and a Strive for Hope

The initial emotional impact of the diagnosis appears to be variable across the studies included in this review. For some participants, there was acute anxiety and a newly developed fear of falling, fracture, and visible signs of the condition appearing. For these individuals, acceptance and readiness for interventions was a quick process (Hansen et al. 2014). Conversely, others did not consider the diagnosis to be an issue (Besser 2012) and used it as motivation to maintain positivity (Nielsen et al. 2013).

The defining factor between a path of fear and one of positivity appeared to be the presence of fracture: For those who were yet to experience fracture, the future, perversely, appeared bleak. For those who had experienced fracture but had healed and continued to live with the condition's invisibility (that is that they had no visible deformity or spinal stoop) there was a drive to tell people to live life to the fullest-as they never know what may come their way (Nielsen et al. 2013).

The predominant emotion for an individual with osteoporosis appeared to be one of fear: Fear of becoming a stooped old person and looking like one's mother or grandmother (Paier 1996; Besser et al. 2012; Hansen et al 2014); fear of the unpredictable consequences of the condition (Paier 1996; Roberto and Reynolds 2001); fear of becoming a burden later in life (Roberto and Reynolds 2001); fear of getting cancer due to osteoporosis medication (Roberto and Reynolds 2001); fear of losing one's independence and becoming more reliant on and therefore a burden to, friends and family (Roberto and Reynolds 2001; Besser 2012; Hansen et al 2014); and finally fear of falling (Roberto and Reynolds 2001; Hallberg 2010). But, the ultimate fear was the fear of fracture. This was especially true for those who felt they always fractured when they least expected it (Paier 1996). Individuals felt a vulnerability from imagining their bones would not heal well, with fears that each fracture would be more severe than the last and that the next fall could be fatal (Paier 1996; Hallberg 2010; Nielsen et al. 2013; Sale et al. 2012). These fears caused individuals to see the world as a more dangerous place (Paier et al. 1996). Knowledge about the implications of a fracture and the risk of fracture induced a fear and insecurity into the everyday lives of those with osteoporosis (Nielsen et al. 2013).

The fear of fracture was closely associated with the fear of losing one's independence. Those with osteoporosis wanted to maintain their own environments and feared becoming dependent on others should they fracture again (Roberto and Reynolds 2001; Hallberg 2010). Not wanting to be a burden to their children, not wanting to be a burden to family and friends on social occasions and a fear of being a burden if one were to fracture again, were each reported as considerations for those with osteoporosis (Hallberg 2010). Individuals reported experiencing *health* if they could manage on their own and take care of themselves whilst not feeling dependent on others (Hallberg 2010). This independence appeared to not only refer to a physical independence but also an ability to control one's own life and realise ones goals in life, for emotional independence (Roberto and Reynolds 2001; Hallberg 2010).

The uncertainty of when fractures might strike, if or when pain may return, and worries about the future were made worse through the silent nature of the condition that could only be monitored through DXA scanning (Paier 1996; Besser 2012; Nielsen et al. 2013). The lack of control and mastery over the condition that is difficult to monitor regularly, led individuals to either live day by day or live with an expectation that the worst will happen, with pain and dependence being dominant in their old age (Hallberg 2010).

Worries over the future and loss of hope for an active and painless old age, were increased if another older family member, for example mother or grandmother, had also had the condition (Nielsen et al. 2013). Some reported a fear that they are shrinking, not just physically but that their life opportunities are also reducing as a result of the diagnosis (McKenna and Ludwig 2008).

Hope, however, was evident with hope for new treatments, hope of escaping the consequences of osteoporosis and a hope of no further fractures (Paier 1996; Hallberg 2010; Besser et al. 2012; Nielsen et al. 2013). The ability to retain hope or feel hopeless appeared to be more related to the person's network and outlook on life in general, than the deterioration of their condition (Nielsen et al. 2013).

ii. Impact on self-image

Most upsetting for individuals with a diagnosis of osteoporosis is a physical presentation of their condition. Stooped posture, spinal curvature and mourning the loss of their height and posture have all been reported (Paier 1996; Roberto and Reynolds 2001; Hallberg 2010). The image of a "crone like" old woman haunted female participants in particular, as they remembered the images of someone they knew who had a marked stoop in old age (Paier 1996, p.33). The reduction of height was seen as a concurrent reduction in life's opportunities (McKenna and Ludwig 2008; Besser et al. 2012). The image of being a shrunken old woman, growing old before their time, was particularly upsetting but initiated a motivation for adhering to interventions such as physical activity or medication, to try and keep that potential outcome at bay (Hallberg 2010; Roberto and Reynolds 2001; Besser et al 2012). The imagery and fear of stooping, that affected self-image so drastically, were heavily associated with posture with negative comments about deviations in posture from family members causing hurt and upset (Paier 1996; Hallberg 2010). Posture bras and braces were utilised by individuals to help them stay in an upright posture and prevent deterioration (Paier 1996; Hallberg 2010; Besser et al. 2012). Perceptions of their own body gauged how serious the diagnosis might be and how much anxiety the individual needed to attach to that diagnosis (Weston et al. 2011). The male perspective on body image is addressed separately in section 2.6.

iii. Managing Visibility

The external visibility of osteoporosis depends on the nature of its manifestation within the individual. For some there were no visible signs of the condition, for others, spinal curvature or visible deformity from a fracture was evident, particularly in the case of vertebral fractures (Hallberg 2010). Pain and physical impairment from fractures were common, yet invisible, occurrences (Besser et al. 2012). Relative visibility was a double edged sword for many with osteoporosis. For some, if osteoporosis remained invisible to them, having not experienced fracture, pain or

perceived postural alterations then the disease continued to be a minor part of that person's life (de-Souza et al. 2010; Weston et al. 2011). No limitations were placed on everyday activities, and total independence and autonomy were enjoyed (de-Souza et al. 2010). This allowed the continuation of a healthy view of themselves from pre diagnosis (Weston et al. 2011). This invisibility, however, caused issues when trying to comprehend having a condition for which there were no symptoms but severe potential consequences (Hallberg 2010; Weston et al. 2011). Similarly, some felt that the invisibility of their condition meant that they were not respected by medical professionals when trying to seek support for back pain as their symptoms was invisible (Hallberg 2010).

When visible (either by DXA result, fracture, pain, deformity or limitations to daily activities, or a feeling of being afraid of falls), acute sadness was felt as the condition was taking an unfavourable course (de-Souza et al. 2010; Hallberg 2010; Weston et al. 2011).

2F. Non-traditional patients for osteoporosis

The systematic approach to the literature search adopted for this literature review, produced only 13 patient experience papers over a period of 21 years. There is an obvious paucity of literature addressing the patient experience of osteoporosis, especially the non-traditional patient group of premenopausal osteoporosis. The literature search did, however, generate two articles exploring the complexities of living with osteoporosis for the only other non-traditional/non-stereotypical population for the condition, males – those of Nielsen et al. (2011) and Solimeo et al. (2011).

By age 65, men and women lose bone mass at the same rate but men do not experience the rapid loss of bone due to sudden oestrogen loss at menopause that women experience (Francis 1999; Gennari and Bilezikian 2013). Nielsen et al. (2011) completed a qualitative focus group based study with 20 male participants aged 51 to 82 years old. Their findings highlighted males who presented with little obvious

physical impairment as a result of osteoporosis would describe themselves as having *no problems* despite actually having a comprehensive history of osteoporotic fractures. As long as the men could carry out the daily tasks that were important to them, they considered their osteoporosis as being non problematic even if these tasks had to be modified in some way to accommodate a limitation of pain or function. Maintaining a sense of self and independence was important to all men in the study. All noted that the medical information they had received (with reference to recommended lifting loads) was not applicable to them, as they were men and so stronger than older females, for whom they felt all available information was written (Nielsen et al. 2011).

Males have been found to report elsewhere, that the information they obtained about the condition, either through health care practitioners or through their own independent searches, did not apply to them and at times contradicted their previous understanding of a healthy diet and lifestyle (Raphael 2008). Expectations of gender roles and masculinity coloured each of the findings of the Nielsen et al. (2011) study yet the themes presented could also be applicable to the female who is also wanting to maintain a level of normality, is stronger than the typical older, more frail, postmenopausal female for whom all information is aimed and for whom the diagnosis has impacted the sense of self.

Within the Solimeo et al. (2011) study 23 males over the age of 50, completed semi structured interviews in which the first part aimed to collect responses to the five constructs of an explanatory model: Diagnosis, treatment, cause, nature, and course. The second part of the interview was open ended. Whilst this study explored specific constructs rather than allowing free flow patient experience data to evolve the findings are a useful addition to the non-traditional patient experience literature for osteoporosis. The men reported dissatisfaction with the side effects of their bisphosphonate medication and were concerned over its safety and efficacy as little data was available for their population. Pain medication also caused concern over potential addiction in some cases and its lack of strength in dealing with their back pain reported by others. Each of the men had anchored their diagnosis to a

particular element of their lives, ranging from cancer treatment to milk aversion as a child (Solimeo et al. 2011).

The men in the Solimeo et al. (2011) study measured their condition severity by fracture incidence, pain, and BMD scores. The latter provided hope for their prognosis if it had been shown to have improved - although any lessening of BMD resulted in dismay. Participants explained their negative feelings towards prognosis were as a result of limited knowledge about osteoporosis in men. The men's responses to interview questions highlighted feelings of uncertainty, frustration and gender identity. The issue of gender stereotype for the condition was evident in: The delay in diagnosis - due to osteoporosis not being considered by health professionals for males with fracture episodes; adherence to medication - that was perceived to be designed for women; and the efforts by individuals to continue to work through pain episodes to fulfil their expected manly duties of lifting and carrying heavy objects (Solimeo et al. 2011).

2G. Chapter Summary

It can be seen from this review of the literature that the experience of living with osteoporosis is multidimensional. The biomedical experiences of those with the condition have a direct impact on their emotional response to their diagnosis with the majority of individuals reporting dissatisfaction with the medical profession and their level of knowledge on the condition. This dissatisfaction in information transfer is even more evident in men, and women of premenopausal age, perhaps due to the lack of literature on the impact of the diagnosis on these populations available to medical professionals. Social support is important, in terms of supporting the emotional journey for those with a diagnosis, but seeing others in a more grave position than the individual, only serves to cause upset and anxiety.

The emotional journey is one of fear, uncertainty and an element of hope. This journey is impacted by previous health care experiences, personality, the nature of the condition and one's reaction to biomedical and social experiences. Negative

emotions are heightened when the condition becomes more visible to the individual such as during pain episodes, fracture or a physical deformity. The image of a "crone like" woman (Paier 1996, p.33) with marked spinal curvature is one that haunts females. When combined with a fear of losing one's independence due to the condition, the image provides motivation to make lifestyle changes to enhance wellness and promote physical activity and positivity. The feeling of uncertainty over the current condition status, potential progression and future outcome of the condition is exacerbated by its silent nature. Whilst for some, the lack of visibility allows an element of *out of sight out of mind*, for many the invisibility causes more anxiety and a harder emotional journey. For males with a diagnosis of osteoporosis the implications of the stereotypical view of an individual with osteoporosis being an old postmenopausal female results in them feeling the information available is not applicable to them as they are stronger then the stereotypical presentation.

For the premenopausal female, there is the added complication of an even greater lack of awareness of both the condition and its potential impact demonstrated within the medical profession due to ambiguity over diagnostic criteria, indications for scanning, pharmacological interventions and the progression of the condition with oestrogen loss, post menopause.

2H. Aim and Research Question

Due to the considerations detailed above and the paucity of literature on the patient experience of premenopausal osteoporosis, the aim and research question for this PhD study were as follows:

AIM: To explore the experience of living as a young active woman with a non-traditional presentation of osteoporosis, premenopausal osteoporosis.

RESEARCH QUESTION:

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

CHAPTER 3: METHODOLOGY

3A. Introduction

Having explored the literature associated with the experience of living with osteoporosis, it can be seen that there are only a limited number of accounts. These address the experience of both the postmenopausal female population and, to a lesser extent, the male population. There is an absence of accounts of those experiences from females with premenopausal osteoporosis. The question, *How has a young female experienced living with osteoporosis?* has remained unexplored and so the research question guiding this thesis will be the first contribution in this area. Answering this research question will add breadth and depth to patient experience literature by incorporating the condition of premenopausal osteoporosis, whilst exploring the implications of being a non-traditional patient for a condition.

This chapter details the processes undertaken in finding the most appropriate methodology and method by which to answer the research question (How have I, an active young female, experienced living with premenopausal osteoporosis?). The development of the methodology has been influenced by a number of factors that I have summarised in the following table:

FACTOR	DETAIL OF IMPLICATION
The theoretical position adopted for this PhD research.	With a number of paradigms and their associated epistemological and ontological assumptions available to any researcher, the philosophical position adopted for this PhD drives the chosen methodology and method.
The paradigmatic shift in healthcare towards interpretivism to understand psychosocial implications of ill health.	Interpretivism, like life world/lived experience work, comes with assumptions, methodologies, and methods designed to explore subjective experiences.
The research is centred on exploring the experience of living with a condition.	A number of methods can be employed to unpack the experience of living with a condition with differing levels of emphasis on elements of that experience.
The idiographic nature of chronic illness experiences.	Whilst common ground exists between patients' experiences of chronic illnesses, each condition comes with it a unique set of assumptions, preconceptions, implications, and experiences and therefore conditions must be explored separately to bring the experiences of living with these conditions to life.
The lack of previous research in this subject area	An inductive design was needed to capture the breadth and depth of the experience as no other research on the topic is available.
I, the researcher, am also the participant	A number of first person methodologies are available, with each offering benefits and limitations.

Table 4: Factors Influencing Methodological Development

3B. Theoretical Assumptions Influencing this Research

It is important for any research to make explicit the world view of the researcher and the paradigm within which the study is situated. Each paradigm brings with it a complex set of assumptions on knowledge and reality, which impact on both the choice of methodology and method. Stating the chosen perspective also ensures the research is appraised by the appropriate standards for evaluating its rigour and trustworthiness (Haverkamp & Young 2007).

A paradigm is a set of interrelated beliefs about the world that provide a philosophical and conceptual framework for the organised study of that world (Ponterotto 2005). That includes ontological, epistemological and methodological

assumptions (Morrow 2007). The paradigm identified by the researcher guides them in both the philosophical assumptions about their research and the selection of tools, instruments, participants, and methods used in the study (Denzin & Lincoln 2011). The paradigmatic stances are so diverse that evolution or reflection in one paradigm is not necessarily applicable to the others (Vasilachis de Gialdino 2009) thus making the explicit statement of the research project's guiding philosophy important in order to establish the contribution to both knowledge and theory.

Paradigm	Ontology	Defining Features
Realist	Reality exists separate from the perceiver. Definite knowledge can be identified.	Objectivity is necessary. Postpositivism differs from its forerunner, positivism as reality can only be apprehended imperfectly. Multiple methods and investigations are required, and knowledge is identified through convergence of findings
Interpretive	Relativist, in that multiple, equally valid social realities exist.	Knowledge or meaning emerges through interaction between persons and is described as co-constructed; it cannot be observed directly but must be interpreted. Researcher values are assumed to influence the research process
Critical	Critical realist ontology. A discernible reality exists, but this reality reflects the oppressive influence of social, political, and historical factors	The researcher's role is both interactive and proactive, with the explicit goal of facilitating change and emancipation from restrictive social conditions. Values are an explicit component of the research endeavor and are based in a sociocultural critique.

Table 5: Comparison of paradigms, their ontology and defining features adapted from Haverkamp and Young (2007, p.268)

i. Identifying the Paradigmatic Position of the Researcher

Having graduated with a BSc in Sports Rehabilitation and Health and Human Biology in 2001 and gaining an MSc in Sports Science and Medicine in 2006, I have worked as a Sports Rehabilitator and Musculoskeletal Performance Consultant for 17 years. During this time I treated sports injuries within multiple sports people and trained

professional football and rugby players to ensure their technique was both efficient and consistent. My training and professional mind-set has been one situated within the realist paradigm defined by Haverkamp and Young (2007) as a single knowable reality with the existence of general laws. I would read research papers and apply these laws and principles to the systematic rehabilitation of client injuries, measure outcomes and progress and have defined end points for my engagement with injured individuals. My position within the staff supporting professional sports teams, enforced and maintained my detached manner and a focus on outcomes and 'the injury,' rather than engaging in an understanding of the individual to whom the injury was associated. This worldview reflected the original and dominant paradigm within medicine; a relativist theoretical perspective represented by the biomedical model (Laing 1971) in which health was seen as the absence of disease, (any pathological or anatomical findings that are divergent from those considered normal for normal functioning) (Boorse 1981). The biomedical model focused on the body as a mechanical interaction of body parts that work to create function. Causative factors of a disease were merely objective findings that needed to be eliminated by medical interventions, in order to cure a patient and re-establish health (Lundstrom 2008, Marcum 2008).

The disease orientation of the biomedical model has evolved due to the growing awareness that health is made up of more integrated elements than previously assumed. The World Health Organisation's 1948 definition of health is still used to this day. It developed the biomedical model to include a social, humanistic viewpoint by stating "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO ca.2014). With this increased humanistic perspective, health is seen as an ability to function in relation to ones goals, resources and within one's social context (Seedhouse 2001; Nordenfelt 1997).

The biomedical model evolved into one that recognised the individual, the social context in which they live and the system devised by society to deal with the disruptive effects of illness, (that is, the physicians role and the health care system in

which they and the patient are situated). This new model was termed the Biopsychosocial model (Engel 1977) and its application to health care provision would mean that the health care professional should treat patients as a whole by: incorporating the patients' lived experience in a psychological and social way; acknowledging both the objective and subjective dimensions of any present disease; including patient's narratives in diagnosis and treatment (Switanowsky 2000).

The NHS within the UK has recognised this paradigmatic shift towards the interpretive perspective and made efforts to move away from the traditionally paternalistic model of health care (Coulter 1999; Haverkamp and Young 2007). The paternalism was characterized by physicians and health professionals being regarded as experts and the patient contribution to the model only being their illness (Bodenheimer et al. 2002). The paradigmatic shift has therefore moved the NHS towards a system where health care provision is more person-centred. This drive has resulted in the patient /person now being placed at the heart of the health care system (Department of Health 2010) through "shared decision making, self-managed support and personalised care planning" (Coulter and Collins 2011, p.2).

My move to academia, in 2007, was the catalyst to a change in my worldview from Realism to Interpretivism, for reasons that mirror the paradigmatic shift in health care. Once in academia, no longer were the people for whom I was responsible, a single presentation of injury that needed to be *fixed* through the application of scientifically evaluated treatment protocols. I was now responsible for the undergraduate journey of up to 145 students per year group, many of whom needed pastoral guidance addressing a broad spectrum of issues, that in some cases threatened the student's ability to graduate from their chosen programme of study. Whilst the results of these journeys were still measurable, in terms of pass marks and student satisfaction, I became acutely aware that for most, the immeasurable experience that the students had been through, was more important to their journey through university, than the grades they achieved. Having now been working as an academic in Higher Education for 9 years, my world view has shifted to adopt the ontological and epistemological assumptions held within the interpretivist paradigm.

Within the paradigm of interpretivism, relativist ontology is assumed. The relativist belief is that multiple and equally valid social realities exist, with reality being constructed in the mind of the individual (Hansen 2004). This constructivist element is that reality is subjective and influenced by the context of the situation, for example, the individual's experience, perceptions, social environment, and interactions. Causal relationships are not sought as a truth. Reality is not a unitary objective phenomenon (Hansen 2004). The etic perspective that "universal laws and behaviours [exist] that transcend nations and cultures" (Ponterotto 2005, p.218) does not apply. Within interpretivism there are as many truths and realities as there are perceivers (Hansen 2004). The researcher working within this paradigm aims to gain an emic/insider perspective (Merton 1975; Ponterotto 2005). This perspective refers to the constructs and behaviours that are unique to an individual and their sociocultural context (Ponterotto 2005) allowing the interpretation of meanings, values and explanations to uncover the multiple truths that exist (Richardson 2017).

ii. The Paradigmatic Position of this PhD

This PhD is situated within the interpretive paradigm introduced above. This paradigm can be traced back to Kant's *Critique of Pure Reason*. Kant's view was:

> "In respect of time, no knowledge of ours is antecedent to experience, but begins with it"…"But, though all our knowledge begins with experience…it is quite possible that our empirical knowledge is a compound of that which we received through impressions and that which the faculty of cognition supplies from itself..so the question is …whether there exists a knowledge altogether independent of experience (a priori), in contradistinction to empirical knowledge, that has its sources a posteriori, that is, in experience" (Kant and Meiklejohn 2011, p.v).

Kant highlighted that human claims about nature cannot be independent of the inside-the-head processes of the knowing subject, that is, you cannot separate an objective reality from the person who is experiencing, processing and labelling that reality (Kant and Meiklejohn 2011). Research based within this paradigm, therefore, seeks understanding. It seeks to describe and explain relationships from the viewpoints of those being investigated; to take into account the intangible aspects of being human (such as feelings and emotions) and the role these concepts play in explaining behaviour. This ontology is fundamental in achieving the depth of

meaning and understanding that is required to answer the research question for this present research. With ontology being concerned with the nature of reality, epistemology is concerned with how this reality is captured or known, how knowledge is acquired and what counts as knowledge (Gratton and Jones 2010) and the relationship between the researcher and the reality. The researcher's intent is to make sense of, or interpret meaning about the world, and therefore generate, or inductively develop, a theory or pattern of meaning as a result of these interpretations (Haverkamp and Young 2007).

3c. Qualitative Research

Working within a paradigm that is focused on meaning and interpretation, one is naturally drawn to qualitative research, in order to answer the research question How have I, a young active female, experienced living with premenopausal osteoporosis? Whilst two main forms of research exist, qualitative and quantitative, quantitative research involves the collecting and converting of data into numerical forms, in order that statistical calculations can be made and conclusions drawn. This deductive process is reliant on objectivity is not appropriate for answering the research question for this study which involves exploration of experiences (Ponterotto 2005). Qualitative research, however, aims to capture meanings and qualities such as feelings, thoughts, and experiences that are not quantifiable (Denzin and Lincoln 2008). Qualitative research has its roots in anthropology, sociology, education, psychology, history, and literature and there are a number of different qualitative approaches available to the researcher (Ponterotto 2005). Qualitative research is designed to study the experiential life of people, "to describe and clarify experience as it is lived and constituted in awareness" (Polkinghorne 2005 p.138). Data is gathered that is rich, descriptive and illustrates the phenomenon of interest intensely (Polkinghorne 2005).

Qualitative research is appropriate if one needs to present a detailed and in-depth view of a phenomenon (Morrow 2007). When theories are not yet available to explain phenomena, qualitative designs are used in order to facilitate the theory-

building process (Morrow 2007). Similarly, when a process or phenomena is not well known or understood, qualitative research may bring new or unexpected knowledge to the fore (Lietz and Zayas 2010). Qualitative research is emic and idiographic as categories that emerge from the data are from the 'insider' (emic) perspective of the participants (Morrow 2007).

i. Exploring Qualitative Quality

One of the criticisms of qualitative research is that qualitative studies lack the scientific rigour, generalisability, and credibility associated with traditionally accepted quantitative methods (Sparkes 2002; Vaismoradi et al. 2013). Lincoln and Guba (1985) presented early quality criteria that paralleled the established criteria within quantitative research (those of internal validity, external validity, reliability and objectivity (Sparkes and Smith 2014). Lincoln and Guba (1985) stating that qualitative research must achieve the overall aim of trustworthiness; an aim that would be met if the research demonstrated credibility, transferability, dependability and confirmability. Within this context, credibility referred to confidence in the truth of the findings; transferability involved the demonstration that the findings have applicability in other contexts; dependability was achieved if the findings were consistent and could be repeated, and confirmability highlighted the degree of neutrality within the research, that is, the extent to which the findings of a study were shaped by the respondents and not as a result of researcher bias.

In order to demonstrate each of the components of trustworthiness, Lincoln and Guba (1985) proposed a number of techniques that qualitative researchers could employ within their research. A study's credibility could be made explicit through the employment of techniques such as prolonged engagement, persistent observation, triangulation and member-checking data. In order to present dependability an inquiry audit is offered as a means of documenting the process by which a researcher outside of the research examines the process of data collection, data analysis and the result of the research study. This is done to confirm the accuracy of the findings and to ensure the findings are supported by the data collected. Confirmability can be demonstrated through the use of an audit trail

within which the researcher details the process of data collection, analysis and interpretation through recording what topics were unique, writing down thoughts about themes and rationale for merging data units together for example. The second part of confirmability is reflexivity in which the researcher must look at his or her, own background and position and see how these influence the research process. Finally transferability is achieved through the use of thick description throughout the work (Lincoln and Guba 1985).

Since the dissemination of the Lincoln and Guba (1985) criteria, others (Bochner 2000; Denzin and Lincoln 2005; Guba and Lincoln 2005) have offered insights about best practices for qualitative research, yet all situate themselves in what Cho and Trent (2006) would call a transactional notion of validity. This approach assumes that qualitative research can be more credible as long as certain techniques and strategies are employed throughout the study – a comprehensive discussion of which can be found in Sparkes and Smith (2014). In opposition to this view are those who have abandoned trying to find parallel criteria for quantitative validity and offer characterising traits (rather than criteria) that highlight the relativism associated with qualitative work.

The most notable of these relativist quality conversations were those of Tracy (2010), Holman Jones (2005) and Barone and Eisner (2012). Tracy (2010) presented eight "Big-Tent" criteria for excellent qualitative research; "a worthy topic; rich rigour, sincerity; credibility; resonance; significant contribution; ethics and meaningful coherence" (Tracy 2010, p.839). Holman Jones (2005) spoke specifically about autoethnography criteria and the inclusion of participation as reciprocity, reflexivity, meaningful dialogue, personal narrative, evocation and engaged embodiment, within the research study (Holman Jones 2005). In relation to judging arts based research Barone and Eisner (2012) suggested; incisiveness, concision, coherence, generativity, social significance, evocation and illumination as the key six areas for quality judgements to be made against. It has been proposed by Krippendorff (2004) that one of the best ways for judging the quality of qualitative findings is simply

whether new insights into the studied phenomenon have been provided so that the study can increase the understanding of particular phenomena.

Ultimately with any list based quality framework, there is the assumption that the more one can tick off the list, the better the research must yet as Sparkes and Smith (2014) state, this is simply not the case. They advocate researchers carefully choosing the criteria by which they wish the quality of their work to be judged, in order to make quality judgements specific and relevant to that work.

> "Values for quality, like all social knowledge, are ever changing and situated within local contexts and current conversations. As such is it important to regularly dialogue about what makes good qualitative research" (Tracy 2010, p. 837).

ii. Qualitative contributions to knowledge

The incremental contribution to literature (that is a hallmark feature of realist quantitative science) is not necessarily as overtly obvious within qualitative research as quantitative research (Richardson 2007). The concept of cumulative knowledge appears easier to operationalise in fields based on realist ontology and quantitative methods (Richardson 2017). With realism supporting the ideal of a single independent reality, the quantitative researcher's addition to knowledge can be measured against this suggested truth. Explicitly identifying cumulative knowledge is a valid concern for etic qualitative studies (those attempting to extract concepts and findings from the field in order to identify patterns across research sites) while emic qualitative research (such as this present research that will provide rich insights into a specific setting) (Merton 1975; Ponterotto 2005) is traditionally less concerned with making explicit the contribution to cumulative literature (Lett 1996; Richardson 2017). The concept of cumulative knowledge in qualitative emic research reflects the results being part of a conversational debate about the nature of the lived experience. Knowledge is cumulative if it is embedded in a broader field of enquiry and increases the extent and density of intertextual links in that field (Richardson 2017). To this end, a qualitative methodology was needed that not only answered

the research question but that could also produce findings that could contribute to the accumulation of qualitative knowledge (this contribution is discussed later in this chapter).

The next section in this chapter builds on these theoretical foundations and plots the journey to finding the most appropriate researcher-as -participant methodology to fulfil the criteria of both answering the research question whilst adding to knowledge through emic research.

3D. Qualitative 'Researcher-as-Participant' Methodologies

Within qualitative health research individuals' personal stories have been increasingly used as means for researchers to explore elements of healthcare from the patient's perspective. These narrative methods include biographical stories, autobiographies, life histories, oral histories or personal accounts (Denzin 1989). With the research question for this PhD being, *How have I, a young active female, experienced living with premenopausal osteoporosis?* it has been important to explore the development of research-as-participant methodologies in order to find the most appropriate for answering the research question.

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). In addition, researcher-as-participant doctoral work has the potential to "become interwoven with the politics of the discipline and of the wider academic setting" (Dumitrica 2010, p.19). 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). This section of the methodology demonstrates the journey through possible researcher-as-participant approaches in order to ensure the final methodology was the one most appropriate to answer the research question (whilst also making an explicit contribution to accumulation of knowledge and ensuring reflexivity, impactfulness, and aesthetic merit are demonstrated).

The following sections explore three researcher-as-participant methodologies that were considered for the methodological approach for this present research. Each is discussed as part of the journey to finding the most suitable methodology to answer the research question How have I, a young active female, experienced living with premenopausal osteoporosis?

i. 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 an autobiographical genre of writing and research described as a,

> "blend of ethnography and autobiographical writing that incorporates elements of one's own life experience when writing about others" (Scott - Hoy 2002, p.276).

It is a form of self-narrative that places the self within a social context (Reed-Danahay 1997). Stemming from the field of anthropology in the 1970s, autoethnography transcends narration of self, to engage in cultural analysis and interpretation (Chang 2008). Autoethnographers vary in their emphasis on self (auto), on culture (ethno), and on the research process (graphy), with different

examples “falling at different places on the continuum of each of these three axes” (Ellis and Bochner 2000, p.740). 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.”

Through applying the term autoethnography to their work, anthropologists were liberated to bring their personal stories to the centre stage of their ethnographic investigations. Within the social sciences, autoethnographical work has been categorised by Reed-Danahay (1997) as either i) native anthropology in which members of previously studied cultural groups become ethnographers of their own groups; ii) ethnic autobiography in which personal narrative are written by members of ethnic minority groups and iii) autobiographical ethnography in which anthropologists interject personal experience into ethnographic writing. Within each form of autoethnography presented, the individual stories are framed in the context of the bigger story, a story of the society, in order to make autoethnography ethnographic (Muncey 2005).

To achieve this ethnographic intent, autoethnographers must undergo the usual ethnographical research process of data collection, data analysis, and report writing. Data needs to be verified through triangulation and interpreted to decipher the cultural meanings of events, behaviours, and thoughts (Chang 2008). Different forms of autoethnography have since been identified with key authors tending to prefer one type to others. Atkinson (2006) and Anderson (2006) align themselves with analytical, theoretical and objective approaches to autoethnography whilst Ellis and Bochner (2006) and Denzin (2006) argue for a more subjective, evocative and emotionally charged representation of the method.

Health autoethnography has developed in the last 20 years, to provide a voice to those diagnosed with chronic conditions (Ettorre 2010). Some of these research papers do not make explicit the ethnographic contribution of their work and as such perhaps the label autoethnography is not an appropriate one for the research. The

need for visible ethnography and cultural interpretations do not align with the aim and research question for this present research (with its goal of providing an understanding of the experience of living with a condition). The focus on this present research (explored in Chapter One, section 1E – Delimitations) is on the experience of living with osteoporosis. The aim is not to link that experience to the experiences of others as a cultural group. 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 is explored within the next section.

ii. 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 Dithley's (1833-1911) works on how individuals engaged in experiential life, that is their lived experience or life world (Todres and Holloway 2004), in order to address the perceived inadequacies of scientific and objective methods to studying the nature of human existence (Allen-Collinson 2009). Husserlian phenomenology embraced the subjectivity of human experience, underlining Husserl's belief that human experience was the basis of all knowledge.

Different forms of phenomenology have developed since its original works: Constitutive/transcendental (descriptive) phenomenology; Hermeneutic (interpretive) phenomenology and Existentialist (embodied) phenomenology. Constitutive/transcendental phenomenology refers to Husserl's original descriptive phenomenology and addresses the notion that we must set aside our presuppositions about a phenomenon in order to see its 'essence' (Allen-Collinson 2009). Hermeneutic phenomenology developed by Heidegger, Gadamer, and Ricoeur (the latter in particular) emphasises the more interpretive nature of phenomenological inquiry and the meanings connected to our life-world experiences. Existential phenomenology focuses on what it means to be human, whether human nature exists and what it means to be aware of our own mortality. Embodiment and

sensory dimensions are paramount where the world, body, and consciousness are all interwoven and mutually influencing (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).

In so doing, we understand the lifeworld of the research participants in the study (Manen 1997). The resultant phenomenological analysis should present the essence of the phenomenon, the element without which the phenomenon would not be what it is (Strandmark and Hedelin 2002).

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 auto-methodology of autoethnography (see Candib 2004; Foster et al. 2005; Ettorre 2006 and Ettore 2010 for examples) then the more appropriate methodological term would be autophenomenography. Since its introduction as a new method, a limited number of researchers have explicitly adopted autophenomenography to analyse their own phenomena and life-world experiences (see Hockey and Allen-Collinson 2007; Allen-Collinson 2009; Allen-Collinson 2015; Gorichanaz 2015).

Autophenomenography was a potential methodology that could satisfactorily address the research question for this present research. However, 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 biography (as discussed in Chapter One, section 1c). The diagnosis therefore needs to be placed within the context of the life course and biography of the individual. There is a chronological element to the events preceding the diagnosis that might have an

influence on both how, and why, the individual is experiencing their condition in the way that they are. The next section of this chapter explores biographical methodology that 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 narrative story to which others might relate.

iii. Autobiographical 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 distinguish the *autobiographical* research method (in which the end product is a researcher's self-lie-story) from the *Auto/Biographical* research method in which "the interrelation between the researcher's own life – autobiography – and the biography of the researched subject" (Roberts 2002) are explored. With this present research focusing on the researcher's self-life-story of osteoporosis, the method explored was that of *autobiography*.

When used as a research method, the aim of autobiography 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). Narrative accounts such as autobiography can trigger changes of many kinds in both the teller and the listener, yielding meanings that are reciprocally produced by each teller–listener dyad (Brockmeier and Carbaugh 2001). 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. Two concepts are integral in this process; habitus and imagination. Habitus has been described as:

> "our second nature, the mass of conventions, beliefs and attitudes which each member of society shares with every other member of society" (Scheff 1997, p.219),

Habitus allows the making of suggestions about how past events have a bearing on action in the present (Ransome 2010). If readers are able to find something in common with the account given, that helps them to expand their own horizons of insight into, and depth of understanding about, their own lived experiences and the meaning of these experiences, then the aim of the autobiographical research has been achieved (Taylor and Settelmaier 2003).

To this end readers must do their own constructing, reconstructing, and evaluating, whilst the very act of writing forces the autobiographical researcher to engage in a process of self-examination that changes both the self and quite possibly the life as well (Johnstone 1999). Research texts stimulate "ability of mind to speculate upon and to link and assemble ideas related to the research text", that is the stimulation of imagination (Erben 1998, p.9). 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, that 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).

Autobiographical work can 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).

Autobiographical work aims to join elements of personal experience in a document (Denzin 1989) containing the self, the narrative, the audience, the truth and the ethics of disclosure (Townsend and Weiner 2011).

> "Autobiography is unique in allowing us to view an individual in the context of his [sic] whole life, from birth to the point at which we encounter him. Because of this it can lead us to a fuller understanding of the stages and critical periods in the processes of his development. It enables us to look at subjects as if they have a past with successes as well as failures, and a future with hopes and fears. It also allows us to see an individual in relation to the

> history of his time, and how he is influenced by the various religious, social, psychological and economic currents present in his world. It permits us to view the intersection of the life history of men with the history of their society, thereby enabling us to understand better the choices, contingencies, and options open to the individual" (Plummer 1983, p.69).

Autobiographies are, therefore, conventionalised, narrative expressions of life experiences, through which we can start to understand public issues (Denzin 1989, p.17).

> "Know that many personal troubles cannot be solved merely as troubles, but must be understood in terms of public issues and in terms of the problems of the problems of history-making. Know that the human meaning of public issues must be revealed by relating them to personal troubles and to the problems of the individual life. Know that the problems of social sciences, when adequately formulated, must include both troubles and issues, both biography and history and the range of their intricate relations" (Mills 1959, p.226).

Autobiography can take one of three forms Denzin (1989): Comprehensive autobiography documents a person's life from the earliest memories to the present time of writing; an edited autobiography takes the comprehensive account and shortens it to a crisp version of the life story; and topical autobiography focuses on a specific point in the person's life story that is of topical interest (Berg 1995) - an excision from the life of the subject (Denzin 1989). Each genre invites comparison with other (like) kinds of lives and few would argue that they have not learnt something of importance from reading an autobiography (Berg 1995).

Within autobiographical research the individual person stands as the primary unit of analysis; an approach that is "eminently justifiable" where the case in question "is a rare or unique event" (Yin 1994, p.44) as is the case in this present research.

3E. Coming to the Most Appropriate Method

This section discusses each of the aforementioned researcher-as-participant methodologies, in relation to identifying the most appropriate to answer the research question, How have I, a young active female, experienced living with premenopausal osteoporosis? It is the differences in the origins of each

methodology, that is, the founding methodology or philosophy for each perspective, which has ultimately driven the journey to selecting the most suitability methodology for this present research.

Despite the variations in autoethnographic genres (analytic and emotive) and the increasing acceptance of subjective and evocative research that autoethnography serves to foster, it has its grounding in ethnography, "the written account of a culture or group" (Denzin 1989, p.48) that takes the emphasis off the individual and towards and exploration of wider cultural implications. This is not the aim of this present research. 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 this present research focuses on a singular reality, a single exploration of the idiographic nature of osteoporosis for one individual, rather than a cultural study to which the individual adds their own insider perspective whilst acknowledging 'others' and their experiences.

Having ruled out autoethnography as an appropriate methodology, experiential methodologies focusing more on the individual and their experience as their singular truth were explored. Lived experience research often involves an exploration of phenomenology, the philosophy behind the nature of human existence. Autophenomenography, with its origins in phenomenology, would appear to be a suitable methodology in answering the research question and would produce an account of the experience that could be either descriptive or more interpretive. 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 autobiographical 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). Any experience is represented by the biographical journey that has led the individual to that experience within their life story. It is important not to separate out the meanings

and experiences of a phenomenon within life from the chronological settings in which they occur (Erben 1998).

> "We enter upon a stage which we did not design and we find ourselves part of an action that was not of our making" (MacIntyre 2007, p.213).

Osteoporosis has a number of risk factors and potential causes that are hugely important in terms of one achieving their peak bone mass potential in early adulthood (see Chapter One, section 1c for a discussion of factors impacting on attainment of peak bone mass). How one experiences the diagnosis of low bone mass cannot be divorced from the preceding life events, both physical and emotional. Exploring a diagnosis as a snap shot in time does 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.

> "The subject, the individual life, emerges in the dual nature of its distinctiveness … and its connectedness" (Erben 1998, p.15).

This resonance and connectedness can be achieved through the telling of life stories, to which the reader can connect. For these reasons the chosen methodology is one of autobiography (situated within biographical methods), and the following section outlines the development of the method (in the context of increased interest in individual life stories), to further support the use of the method as that most appropriate for answering the research question for this present research.

3f. The Development of Research on Individuals' Lives

The first social scientific concern with biographic perspective did not develop until nineteenth century Germany. The first author to turn life history into an object to be theorized by human sciences was Dilthey (1833-1911) who viewed life story as a whole, an object complete unto itself (Todres and Holloway 2004). It is likely that Dilthey's concern with life and lived experience was one of the European influences that affected Robert Park of the first Department of Sociology in the United States, at the University of Chicago (Plummer 1983). Park saw life documents as:

> "…a means to uncover cultural meanings and changes in individual and group experiences within cultural contexts" (Roberts 2002, p.33).

In the early 1920s, the life history method was developing on both sides of the Atlantic. In Europe it started in the form of the 'pamietniki' movement. These were written autobiographies or memoirs usually solicited through competitions run by newspapers (Chalasinski 1991) with Znaniecki organising the first pamietniki competition in Poland in 1921 (Bertaux 1981). In North America, it was a central part of the Golden Age of the Chicago School of Sociology and resulted in the first sociological use in research in the 1920s. The 300-page life story of Wladek Wisznienski, a Polish immigrant to America, formed the central part of Thomas and Znaniecki's study *The Polish Peasant in Europe and America*. During the 1920s and 30s this, and other life histories carried out by the Chicago School, committed to understand the broad character of the urban condition by using more traditional quantitative methods and survey methods but also the deeper and more detailed exploration of individual lives (Harrison 2009). One example of the "scientific mosaic" approach was the production of Clifford Shaw's (1931) *The Jack Roller* (a life history of a juvenile delinquent) (Harrison 2009, p.xxiv). The commitment to methodological plurality and microanalysis was associated at this time with a major new theoretical development in sociology, and social psychology termed symbolic interactionalism in which Herbert Blumer was a key figure (Carter and Fuller 2016).

Blumer proposed that the study of human behaviour should start with human association (Blumer 1980) – a viewpoint that was not common in America at this time where the individual and society were treated as separate entities (Carter and Fuller 2016). The approach was developed in order to shift the focus from positivist approaches examining society from the top down, to understand the operation of society from the bottom up (Carter and Fuller 2016). Symbolic interactionalism is seen as a theoretical perspective in sociology that looks at the way society is created through "face to face, repeated, meaningful interactions amongst individuals" (Carter and Fuller 2016, p.931).

Quantitative research returned to dominance in the 1930s and 40s (Roberts 2002). As a backlash to this development Charles Wright Mills produced the seminal text *The Sociological Imagination* (Mills 1959). This work stressed that the intellectual craftsmanship of social scientists required attention to biography, history, and society. For Mills in order to understand humankind, research must be sociologically and historically grounded (Mills 1959). The life story and case study work of the Chicago School continued from the 1960s onwards with in depth case studies such Lewis' *Children of Sanchez* (1961) and by Allerton and Parker in the UK, who published a number of individual life stories of the underclass such as *The Courage of his Convictions* (Allerton and Parker 1962)

In the late 1970s, Daniel Bertaux oversaw a working group on the life history methods that began to meet and develop life history approaches. The diverse group consisted of members drawn from a variety of countries. In 1978 a Biographical and Sociology group formed within the International Sociology Association (ISA) and in 1986 this group became a Research Committee within the ISA. The first anthology of biographical research was published in Germany in 1978, by Martin Kohli (Kohli 2013), with an international reader by Bertaux following soon after (Bertaux 1981). Biographical methods had a strong humanist impetus in that they provided a means of conducting research that that gave voice to the socially excluded (Bertaux 1981).

The second influence on the increased attention to lives and the research of individuals was driven by second wave feminism from the 1970s that sought ways to address what was viewed as a male dominated practice of ways of thinking (Okely and Callaway 1992). Elite feminist scholarship was a project to make visible the invisible. An important part of this work was to draw on first-hand experiences in order to understand and situate women's lives within the oppressive social system of male dominance (Stanley 1993). Female scholars found the personally rewarding method of biographical research a form of consciousness raising and offering the possibility for change. The construction of stories of their own lives and personal histories prompted feminist scholars to analyse a variety of ways in which lives of women could be studied in both in the past and the present (Stanley 1991).

The categorisation of the term *women* became a driving force behind the aim to understand diversity of lives in which the position of different women was problematised both in western culture and their disadvantaged position within less developed countries (Rich 2014). Class, race, nationhood, sexuality all became seen to be as integral as gender, in identity formation and the sense of self, as well as systems oppression on a global scale (see Sales 1997; Estes 2017 for examples). The feminist movement drove the development of women's studies and then gender studies as distinct disciplinary fields after which black studies grew through the production of autobiographical accounts of lives historically situated (Ibram 2012). Distinct disciplinarity continued to diversify with life stories and research into genocide and Holocaust survivorship (Siegel 1980; Valent 2002), extreme stories of violence (Bennett 1985; Stewart 2014) and human rights campaigns (Ibrahim 1985; Jolly 2015).

For feminists, the I of the self being written about, was indicative of their own reflexivity and the possibility of writing not just about others but also themselves (Letherby 2000). Stanley (1993) stressed the importance of these elements in feminist scholarship as defining a set of practices and methodological procedures that is auto/biography.

In the 1980s there was a concurrent focus on oral history research (Leavy 2011). The oral history research method was concerned with the remembering of the past, "to explore how people are connected with the past, how they viewed themselves as actors within particular historical and social contexts, and how the past was part of individual lives in the present" (Harrison 2009, p.xxv).

The more recent trends of the 1980s onwards brought to light Plummer's (1983) published work *Documents of Life* to develop and make prominent, life stories. Life story research was a humanistic method which he defined as:

> "getting close to living human beings, accurately yet imaginatively picking up the way they express their understanding of the world about them, perhaps

> providing an analysis of such expressions, presenting them in interesting ways and being critically aware of the immense difficulties such tasks brings" (Plummer 1983, p.2)

In the UK this ground-breaking text traced the roots of life story work and provided a basis for research in the sense of how it might be done. It raised issues about how the telling of stories was achieved and the meaning of lives established. The study of biographical research rests on a view of individuals as creators of meaning for the basis of their everyday lives (Plummer 1983). Miller (2000) has developed this work and outlined three approaches to the study of life stories and life histories:

> "Firstly the realist approach uses induction…employs saturation…and unfocused interviews, and considers reliability as important. Second, the neo-positivist approach is deductive, theory testing, uses focused interviews and places important on validity. Finally, the narrative approach sees 'fact' as secondary to an exploration of the ongoing construction of an individual's unique standpoint, uses life or family stories, and emphasises the interplay between the interviewer and the interviewee in structuring reality (Miller 2000, p.10).

All biographical studies presume a life that has been lived is a life that can be studied, constructed, reconstructed and written about (Denzin 1989, p.28). Within this context, life, refers to two phenomena: i) lived experiences or conscious existence and ii) the person – a self-conscious being, as well as a named object of cultural creation. Our self- consciousness involves the simultaneous drawing into ourselves and our inner world of thought and experience (the phenomenological stream of consciousness) and to an outer world of events and experiences (the interactional stream of experience) (Denzin 1984).

Within biographical / life story writing, three core elements have been identified: "A life lived" being what actually happens; "a life experienced" consisting of the images, feelings, sentiments, desires, thoughts, and meanings known to the person whose life it is; and "a life told" is a life history as a narrative, influenced by the cultural conventions of telling, both by the audience, and by the social context' (Bruner 1984, p.7). Biography (life writing) comes in multiple forms, lengths, focuses and perspectives and is labelled with differing terms depending on the emphasis and

structure of the piece; portrayals, portraits, profiles, memoirs, life stories, life histories, case studies, autobiographies, journals and diaries to name a few (Smith 1994). Each involves studying, constructing and writing about lives or parts of lives (Roberts 2002; Jones 2003).

The progression of the biographical method in the 1980's - to broaden the scope and context of individual life story research - is referred to as the Biographical Turn (Wengraf et al. 2002) and is discussed in relation to health care in the next section.

i. The Biographical Turn in Health Studies

Since the 1980s there has been an increase in the use of biographical methods in health studies (Rickard 2001). Biomedicine has been criticised for omitting the patients' lived experience of conditions, and so biographical methods were used to humanise medicine and address this balance. The movement considered the stories of patients through the utilisation of health narratives. This shift involved the change in power between professionals and recipients, through a reconceptualisation of patients as,

> "complex individuals powerfully conditioned by familial and early childhood experiences on the one hand and as consumers with demands and rights on the other" (Hogarth and Marks 1998, p.147).

The introduction of biographical methods in healthcare literature was seen as ground-breaking in promoting participatory and inclusive approaches to health research (Rikard 2001). Biographical methods were seen as an important development and allowed the exploration of models of illness to highlight the disconnect between professional and patients' perceptions of the impact and experience of medical conditions (see Ternulf Nyhlin 1990; Callaghan and Williams 1994; Pinder 1998 for examples of this work). Studies in the early years of the turn to biographical methods in health care, also highlighted social and cultural issues that were frequently underestimated by clinicians, and so this research acted as a catalyst in reshaping future practice and policy (see Whiteford and Gonzalez 1995 for an example addressing the stigma of infertility).

Patterns of adult health and even mortality are clearly linked through social determinants of health presenting throughout the life-course, creating associations between the presentation of conditions and events 50 or 60 years beforehand (Wilkinson and Marmot 2003). Biographical methods allow the drawing on patient narratives to provide meaning, context, and perspective for the patient experience and help explore the life altering capabilities of illness (see Bury 1982; Frank 1995; Exley and Letherby 2001; Sparkes and Smith 2003 for example). Both narrative and medicine are deeply embedded in the world of human troubles and expectations that have gone awry (Harter and Bochner 2009, p.114). Diagnosis or illness narratives, in particular, encourage empathy, promote construction of shared meaning, and enhance the inter-connectiveness of people's lives (Rickard 2001).

The care of the sick unfolds in stories:

> "From the beginning of symptoms to the completion of treatment, illness has to be told – first, through symptoms, by the body of the patient to the patient himself or herself, then to family or friends, and then to professionals, who repeat it amongst themselves. Each illness or episode of care generates multiple accounts: concerns spoken by the patient, reports written by the listening clinician, comments given by other providers, and subsequent responses by all participants to these reports. Each of these accounts represents a singular point of view and purpose. Despite their great textual variation, together they represent a multi-voiced narrative of illness that is fundamental to and determining of its care" (Charon 2012, p.2).

Singular accounts of illness cannot be summarised or collated with data from others, each particular person has their own story that has to be "respected and recognised and hailed as significant" (Charon 2012, p.2). Single case stories of health experiences evident in literature include Ettorre (2006) in which she explores her condition of Thyrotoxicosis; Candib (2004) documenting her journey for diagnosis and treatment of pain in her thumbs; Scarfe and Marlow (2015) in which Scarfe's journey through running with epilepsy is presented. Each story allows the reader to utilise their human characteristic of imagination, to gain an understanding of the experience. This understanding can help both the medical profession (Arntfield et al 2013) and others for whom an element of the story may resonate (Erben 1998).

3G. Autobiographical Research

The basic tenants of autobiographical work have been set out earlier in this chapter in section 3D. This section therefore takes a deeper look at some of the implications of choosing to complete research using this methodological approach. Autobiography has previously been seen as a "contentious issue" as it "involves working at the margins of established research paradigms and academic writing protocols" (Letherby 2000, p.97). There are some criticisms aimed at life story research approaches, for what has been viewed as an excessive individualism – mostly from those who do not follow the worldview that it is in understanding how individuals construct meaning that then provides us with knowledge of how social reality is itself constructed (Harrison 2009). The perspective of symbolic interactionalism, however, shifted attention in the 1930s to the interpretation of subjective viewpoints and how individuals make sense of their world from their unique perspective (Carter and Fuller 2016). Individual biographies, seen as providing distinctive trajectories, strategies and starting points for understanding, are contingent on time, space and the social structures in which they are located (Rustin 2002) so much can be learnt about the individual and society from their production (Erben 1989).

Fischer-Rosenthal's (2000) term *biographical work* refers to the construction of biography and addresses the means by which individuals orient themselves to social and historical situations by recalling the past, interpreting the past, and present, within the self and in other contexts through which temporal ordering in the story, is addressed. There is a risk that autobiographical stories "freeze events and lived experiences into rigid sequences" set within this broader context (Helling 1988, p.240) but autobiography is a process of "life-making" that is a cognitive achievement rather than a clear recollection (Bruner 2004, p.692). Stories (such as those produced in autobiographical work) happen to those who know how to tell them and as such autobiography might be better viewed not as a record of what has happened in one's life but a continuing interpretation and reinterpretation of a personal experience. As self-autobiographical researchers, we become the autobiographical narratives by which we tell about our lives (Denzin 1989).

These life stories however do not happen in the real world but are constructed in people's heads, that is, world making is the principle function of the mind (Bruner 2004).

> "Ethnographies, biographies and, autobiographies rest on stories which are fictional, narrative accounts of how something happened. Stories are fictions. A fiction is something made up or fashioned out of real and imagined events. History, in this sense, is fiction. A story has a beginning, a middle and an end. Stories take the form of texts. They can be transcribed, written down and studied" (Denzin 1989, p.41).

As Denzin states, "all we have are words" (Denzin 1989, p.78). These words are learned from others, yet are spoken or written by us, and are all that we have through which to pour out our inner selves to ourselves (Derrida 1972).

> "There is no clear window into the inner life of a person, as each window is always filtered through the glaze of language, signs, and the process of signification" (Denzin 1989, p.14).

The self will see the life from a different point of view at different points in the life. An autobiographical researcher's 'present' determines their perspective on the past and produces a different past at different times. The present perspective will impact on the selection of memories, the temporal linkage of those memories and the types of representations that those remembered experiences elicit (Usher 1989).

> "…the autobiographical process is conceived as a recounting of a fixed, unmediated and preserved, summonable past (the past as presence) by a self-conceived, independently existing person giving meaning to that experience, a meaning which is present (the self as presence) – both the past and the self being representable and knowable and communicated directly and transparently. Autobiography is thus conceived as a practice that must assume centred time and a centred self" (Usher 1989, p.19).

Narrative accounts, therefore, refer not only to the past experience but also the current life. The past is constituted out of the present and anticipated future, and so the present arises out of both the past and the future.

> "The 'self who writes' does not have unproblematic access to the past and thus – to the 'self who writes' – the past has to be recovered in traces and hints, rather than appearing to us whole and entire in our minds; and for the 'self who is', time moves on outside of the text, so that the 'self who writes' becomes a part of the 'self who was', a part of the past and the sets of multiple overlapping but not coterminous stages in the assemblage of the

> 'self who is currently.' Moreover the 'self who was' is an object for attempted reconstruction by the 'self who writes: this other self becomes a project for, indeed an invention for, the writing self" (Stanley 1993, p.48).

When reconstructing the past (a life history), presented in the present of a life narrative (the life story), it must be considered that the presentation of past events is constituted by the presence of narrating.

Much life story work involves retrospective accounts constructed in the present. As such the factors of memory and time need acknowledgement. It is accepted that since life stories are constructed in the present, they will always be selective, partial, and subject to reinterpretation (Harrison 2009). Kuhn (1995, p.2) argues:

> "Telling stories about our past, our past is a key moment in the making of ourselves. To the extent that memory provides the raw material, such narratives of identity are shaped as much by what is left out of the account – whether forgotten or repressed – as by what is actually told."

There is the potential within the social sciences to segment lives for analysis to such an extent that the overall narrative life has been dissolved (MacIntyre 1985). Both Ricoeur (1992) and MacIntyre (1985) address the implications of this concern over the conceptualisations of actions being divorced from the chronological settings in which they occurred. Time is finite. We are born, we live, and we die. Each narrative is based within this factual context. Of particular interest to social scientists are the social meanings of time, what Riceour (1988) refers to as *human time*. This is not time as chronology (that life story researchers find significant in their work) but time as a non-linear construction, of moments or fragments which is how memory works with time (Ricoeur 1988). Time is therefore not a fixed entity but interpreted and constructed through stories and narratives. For Ricoeur (1988) human time is revealed. The life being lived is composed of the narratives by which time is experienced (Erben 1998).

A studied life is the study of a temporal journey with largely unforeseeable happenings and persons encountered.

> "It cannot be known in advance whether the experiences to be had en route may outweigh the journey's end in their eventual importance and

> impressiveness. Nor can one know in advance whether the journey may change one utterly, in body or in mind. In this particular sense, it is clear that life itself is an adventure" (Gadamer 1992, p.ix).

The past is linked to the future, and when that future becomes the past it will also be linked to another future, but as humans, we do not just free flow through this temporal existence as we are born into a world that is already made, in a language that is already in existence (Erben 1998). Because of this pre-existing schema in which we exist, our interpretations are already partially socialised and influenced by prior significations.

> "All understanding is of necessity mediated by the meaning which is not constituted by the self alone" (Ricoeur 1988, p.168).

So far in this chapter the journey to the most appropriate methodology has been documented, the history of that methodology has been presented and the complexities of the methodology of autobiography have been explored. The following section will set out the process undertaken in completing the autobiographical account for this present research.

3H. Writing the Autobiography

Through the application of autobiographical methods within illness research one can reinforce the aim of interpretive research itself through,

> "Increasing understanding of subjectivity and making subjective experiences more visible and intelligible…Searching for meaning and increasing understanding of the commonality of existential human experience. Decentring the detached observer and his/her privileging the objectivist illusion in the hierarchy of research discourses, paving the way for the admission of multiple realities and interpretations of lived experience" (Johnstone 1999, p.24).

The autobiographical approach used within this PhD study is one influenced by the work of Denzin (1989); Moustakas (1990); Erben (1998); Zammit (1998); Johnstone (1999) and Exley and Letherby (2001) amongst others. These influences have been both theoretical (Denzin 1989; Erben 1998; Johnstone 1999) and through the power of the stories told within their research (Moustakas 1990; Zammit 1998; Exley and

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).

Autobiographical methods are often used to describe "turning point" experiences (Denzin 1989, p.70). These experiences are moments of crisis in which individuals are powerfully absorbed (Johnstone 1999). These moments have similarly been called a “specific event” (Erben 1998, p.7), “epiphany” (Denzin 1989, p.22), or an existential moment (Moustakas 1990). These turning points are rarely planned yet have the potential to change the course of one’s life (Mishler 1999). Within this present research study the turning point experience was the process of diagnosis and the subsequent living with the condition of osteoporosis. By focusing on this element of the researcher’s life, the autobiographical form adopted for this research becomes topical in nature (Denzin 1989; Berg 2009).

The primary sources of data on which the autobiographical account was based, were my personal diary and a blog I started at the time of my diagnostic journey. I have written diary entries ever since I was a teenager. I have always turned to the written word in times of upset as a means of processing my thoughts. For me writing has always been healing. It is a calming activity that cannot be rushed or interrupted; a physical outpouring of my innermost thoughts through the medium of putting pen to paper. I have always felt that I can express myself far better in the written word than when trying to verbalise the same content. Diary writing was a natural and expected process for me that would have occurred regardless of the entries being used for research purposes. 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 and Ryave 2002).

> “Habitual diarists…write their diaries as a way of describing or commenting upon events gone by: earlier that day, the day before, sometimes at further temporal remove. The supposed immediacy of diary writing is hinged to perception of it as a descriptive narrative form, which records from the time and place of the occurrence and is thus more closely related to these than any other form of life writing” (Stanley 1993, p.49).

My final diary entry associated with my osteoporosis was February 2014, almost 3 years post diagnosis, in which I comment I felt no further compulsion to write in order to process my circumstances. This provided a natural end point to the data collection process.

The second source of data was my blog entitled "*My Bones Won't Break Me*" (Hawkes 2012). Whilst the diary writing was always kept private with pages rarely read back once the data entry was complete, an externally facing outlet for thoughts and internal dialogue was used in order for me to raise awareness for a condition for which I had no idea, until that point in 2011, could even be an issue for people like me. The anonymous blog was this external outlet. I started my blog in April 2011 prior to making the decision to complete my doctoral work in this research area. A total of 31 blog entries have been posted, written in a free 'diary' form, with the inclusion of pictures to make the blog accessible to others who might be interested in its content. 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.

In order to prepare for writing the autobiographical account for this present study, a period of immersion was achieved through the reading and re-reading of the data sources, thus surrendering to all of the memories, emotions and imagery elicited to create an intensive and timeless experience of the self (Moustakas 1961, p.ix). Through the process of total immersion in the research data, the method adapted heuristic and phenomenological research approaches that emphasised critical self-reflection (Moustakas 1990; Van Manen 2001). This process was then followed by the writing of an autobiographical narrative that turned the diary entries into a complete document of the life as it was experienced at that time. This document reflected the characteristics of Frank's (1995) chaos narrative in that is was disordered and uncomfortable for others to read.

Like other forms of autobiography, the aim of the autobiographical account within this present research, was for readers:

> "to read themselves into, and be touched by, the final report which is characteristically presented as a formal telling of the self-life-story" (Johnstone 1999, p.25).

In order to do this the specific writing method chosen needed to trigger the imagination of the reader, for them to be able, on some level to "recognise the narrative" that is being told (Erben 1998, p.15). One of the main challenges for all researchers of subjectivity is to write visually, in a way that allows what is felt, to be seen (Johnstone 1999). To achieve this aim, creative writing, without the objectification of the topic through scholarly interjections, was embraced. To answer the research question fully the reader must be able to submerge themselves in my story (Clandinin and Connelly 1994) without referenced interruptions, in order that they might see some of themselves in the work. To be able to experience an account of the self that advances shareable understanding of common human experiences, the reader must be allowed the opportunity to remove themselves from their scholarly identity and experience the prose at their most vulnerable human level, to make resonance possible. The original chaos narrative was revisited over a period of time to create order, sense from the chaos, a narrative that was both readable and yet still allowed the reader to imagine both the context and process of living with premenopausal osteoporosis, as a young, active female.

Writing was expressive, emotional and creative. The orthodox expectations of academic scholarship, by writing a paper "in prose, referencing others, objectifying the focus and focusing on the expressed topic rather than on the self as producer" (Richardson 1992, p.125) were abandoned. This was in contrast to Kirsch (1999, p.82) who stated that the priority in traditional autobiographical data analysis, should be to blend the autobiographical with the scholarly, to:

> "engage the personal in the work, in doing the critical, analytical work necessary to understand how authorial identity shapes, enhances and limits our scholarship".

The result of this process was an autobiographical account of my experience of living with premenopausal osteoporosis as a young, active female that is presented in the following chapter (Chapter Four, Part One).

Following the "intense, concentrated focus" on the autobiographical story I stepped away from the work for a short period of time to allow another level of expansion of knowledge and understanding to take place (Moustakas 1990, p.28). Having engaged in other activities and in so doing, "forgetting about the object of inquiry" (Kenny 2010, p.8) illumination brought with it changes in perceptions dramatically altering my internal frame of reference (Kenny 2010). Incubation directly led to these moments when my mind would suddenly be drawn to a new understanding, new interpretation and new appreciation and conscious awareness of the themes within the autobiographical account (Johnstone 1999). This period of mental space, away from the emotions and recollections of the documented experience, allowed the retracing of events and an exploration of the sense made of them, through the process of reflection. This process encouraged the awareness of qualities and the clustering of these qualities into themes inherent with the research question (Johnstone 1999). The resultant thematic representations (Chapter Five, Part Two) are the reflective expressions and examination of the distinctive qualities, meanings and understandings of the human lived experience (Johnstone 1999).
These themes are then explored with reference to wider academic literature in Chapter Five.

> "The process of beginning with the patient and then extending the research agenda out from the themes embedded in their experiences is especially important for subpopulations who suffer from health disparities or in cases where clinical understanding of the disorder is emergent" (Solimeo et al. 2010, p.531).

The Process of Writing the Reflective Topical Autobiography

The following steps were taken to create the reflective topical autobiography 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 taken as the main prose for the narrative with only the addition of linking sentences to create continuity from one entry to the next. The aim of this stage was 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 the researcher was deeply embedded in the story of their experience.

- A three-week period of Incubation (time away from the research), was then taken by the researcher so that there was space and time to reflect on the main themes evident in the narrative account.

- Each of the themes were then written as a presentation of interpretation of the narrative (the final interpretations are presented in Chapter Four Part Two of this thesis) to demonstrate the researchers reflections on their 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.

3I. Ethical Considerations

The principle of "do no harm" is accepted as central in all ethical research (World Medical Association 2013). Full ethical approval for this PhD research has been granted through the University Ethics Board and is evidenced in the Appendix A. Specific ethical issues related to this present research are presented in this section.

Although qualitative research avoids manipulations or physical damage; it can still be psychologically harmful (Sabar and Sabar Ben-Yehoshua 2017). 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. 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). 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). 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 characters are identifiable by familial relationship such as mother, sister etc (Dushnik and Sabar Ben-Yehoshua 2016). Because of these risks, people and places referred to in this 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 (Appendix B) 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.

There is one character within my story, who is no longer in my life. Due to the nature of our relationship at the point of diagnosis and the subsequent nature of the breakdown of that relationship I am not in a willing position to contact him to gain consent for his place within the research story. This is an interesting dilemma. Whilst referred to as 'my boyfriend' (as he was at the time) and de-identified as wholly as possible through the use of pseudonym and the omission of all identifying features, the behaviours of this character feature in elements of the story without his explicit consent. It is not anticipated that this character will be identifiable to anyone in any way (other than by immediate family reading the account). It is fully possible that individuals within the account, such as this boyfriend, would present a wholly different interpretation of events, yet for this present research the focus is on my interpretation and representation, as it was felt, at a specific time (Bramley and Chapman 2008).

In terms of myself, to revisit traumatic events was of concern in terms of my own mental wellbeing, but 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. My natural tendency to withdraw and not wish to upset friends or family with my recollections and feelings was one that has made this process incredibly painful at times however the passage of time between the experiential

data collection (in the form of diary entries etc) and the completion of the reflective topical autobiography has 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.

3J. Judging the Quality of this Autobiographical Research

Within this chapter, some of the different ways of judging quality in qualitative work have been explored (see page 59). Sparkes and Smith (2014) highlight the importance of researchers choosing carefully the criteria against which they ask their work to be appraised in terms of its quality, with those criteria being relevant to both the aim and method of the research study in question.

When choosing the criteria by which this PhD research should be judged, a number of issues needed to be considered. In taking the quality criteria originally proposed by Lincoln and Guba (1985) it can be seen that to achieve credibility, techniques such as member checking are advised, yet with a researcher-as-participant study, member-checking is a continuous process as the 'member' is the researcher them self. The external researcher audit trail that supports Lincoln and Guba's (1985) criteria of dependability, is not appropriate for autobiographical work, as the researcher is writing the story, from their own present, through their interpretation, recollection and narrative (Usher 1989). Whilst an external researcher could read the story and draw out themes of experience, it is the interpretation of the researcher alone, which is the defining aspect of reflective topical autobiography. The criteria of reflexivity, on the other hand, is overt within the whole piece as the researcher explores their position throughout their biography.

Criteria for judging this present research have been chosen to reflect both the aim of the research but also the aim of autobiographical work; to present an account of the lived experience of the self that advances shareable understanding of common human experiences (Jones 2003). As previously discussed in this chapter, the

account can only achieve this if (through habitus and imagination) the reader can connect to the experience presented, on a human level. Similar to the ethnodrama work of McMahon et al. (2012) the intention of this present research is that the reader would be able to read from the position and perspective of the participant (the researcher) in order that they (the reader) is able to vicariously share that lived experience. Sparkes (1997) says that:

> "focusing on reader response encourages connection, empathy and solidarity, as well as emancipatory moments in which powerful insights into the lived experiences of others are generated" (p. 221).

The quality criteria by which this research should be appraised reflect this desire for connection. Producing a story that is deemed to fulfil the criteria of verisimilitude, evocativeness and enlightenment (Ellis 1999) the intention was to provide the reader with a bona fide sense of what it was like to experience the diagnosis of osteoporosis as a premenopausal female and reveal intimate details privy only to the story teller, to provoke an emotional response in the reader; to penetrate the readers' "heads and hearts" (Ellis 1997, p.131).

The narrative account is said to exhibit the quality of verisimilitude when it has the appearance of truth or reality. It is a criterion for judging the evocative power or sense of authenticity of a text and is a style of writing that draws readers into the experiences in such a way that those experiences can be felt (Schwandt 2007). Through providing an account that has verisimilitude and evocativeness, this present research should present the quality of enlightenment on a number of levels each with the common basis of shared understanding: the reader should be enlightened to their connectedness and distinctness from the story; medical professionals should be enlightened to the experience of those for whom they are engaging in osteoporosis health care; and fellow researchers should be enlightened as to the possibilities of autobiographical research – each of these represents a level of "applied enlightenment" (Geimer 2014, p.24).

The ways in which these criteria were met, is presented in Chapter Six of this thesis.

3κ. Chapter Summary – Choosing a Methodology to Ensure Accumulation of Knowledge

The extent to which this research fulfils the criteria for quality in qualitative work set out by Krippendorff (2004) and the aims of reflective topical autobiography (as specified by Johnstone 1999) lies perhaps more with the reader rather than me, the author of the text. This research fits the postmodern idea that we are all interpreters of life texts and our own reading is of value (Roernau 2001). Using Richardson's typography (2017) for evidencing the contribution to cumulative knowledge from a qualitative research project it can be seen that this PhD research advances knowledge through additions to both the Scope and Depth of knowledge in the fields of osteoporosis and lived experience literature. The context advancement is the addition of an individual's account of their experience of living with premenopausal osteoporosis, a condition for which there is no experience data overtly available. This present research, therefore, provides empirical findings in a new illness "context" (Richardson 2017, p.12). The depth of qualitative knowledge has been advanced through "empirical elaboration" (Richardson 2017, p.14) to provide empirical findings to extend understanding of patient experiences, particularly for individuals who are not traditional patients for a particular condition.

Focus of Cumulative Knowledge	Relevant Literature to be Cited	Macro-Level Framing	Claim to Cumulative knowledge
Cumulative Knowledge of Scope			
Time Period	Studies done on the same topic based on data from other time periods	Periodization	Empirical findings in a new time period
Context	Studies done on the same topic based on data from other contexts	Cultural or institutional variations	Empirical findings in a new context
Theoretical Pluralism	Studies done on the same topic based on data from other theoretical perspectives	Ontological and/or epistemological variations	Interpretation of empirical data from a new theoretical perspective
Cumulative Knowledge of Depth			
Empirical Elaboration	Studies of the same phenomenon / research site using new empirical data	Existing empirical knowledge	Empirical findings that extend understanding
Methodological Pluralism	Studies of the same phenomenon / research site based on data from other methodologies	Methodological Variations	Empirical findings based on a new method of data collection/ interpretation
Theoretical Elaboration	Studies drawing on the same baseline theory	Existing theory	Ancillary hypotheses, boundary conditions, or new theoretical predictions
Analytical Generalization	Theories that have been applied to the phenomenon	Criteria for theory choice	Strong inference tests of the applicability of existing theories

Table 6: Cumulative knowledge and qualitative methods (Richardson 2017, p.23)

This chapter has served to plot the journey to the choosing of the most appropriate methodology to answer the research question, (*How have I, a young active female, experienced premenopausal osteoporosis?*) It has also documented the key phases of research approach taken, that of a reflective topical autobiography. The explicit addition to knowledge that this research will contribute has been articulated.

CHAPTER 4: THE LIFE EXPERIENCED - THE LIFE REFLECTED UPON

4A. Introduction and Chapter Outline

This chapter will guide the reader through a reflective topical autobiography of my experience of living with premenopausal osteoporosis. The chapter is written in two parts. Part One is included to demonstrate the process of data collection for reflective topical autobiography in presenting a story of the "life as experienced" (Bruner 1984 p.7). Part One sets the context of my diagnosis including the "images, feelings, sentiments, desires, thoughts and meanings" (Bruner 1984, p.7) as I saw them throughout that time. This section is written as a continuous prose although there are elements reminiscent of a chaos narrative (Frank 1995) that was my diary, and the more considered blog data collected in real time from before my diagnosis to two years post diagnosis.

Part Two of this chapter is structured in accordance with Johnstone's (1999, p.29) guidance on reflective topical autobiographical writing. Through a process of reflection, the life as experienced is presented as the "life as told" (Bruner 1984, p.7). The "emergent themes, distinctive qualities of the experience, meaning, [and] understandings" (Johnstone 1999, p.27) are presented and excerpts from both my diary and blog writings are used to add words from the chaos that was my diary at that time. These reflective accounts have been produced as a result of the incubation, illumination and contemplations phases of the reflective topical autobiographical method (Johnstone 1999). Chapter Five then develops the analysis of these reflective themes in relation to the wider literature.

4B. Part One: A Life Experienced

My Journey to Diagnosis – December 2011

The story of my experience starts in December 2011. At this point in my life, I was 33 years old. Born in 1978 to two loving and wonderful parents, I had enjoyed a childhood with an older sister, three years my senior, and a younger brother, four

years my junior. I was an active, hockey-playing girl with the privilege of a private school education and a beautiful village location in which to live. I had a childhood that building hay bale houses and village lane family bike rides would sculpt. I moved from an independent all girls' senior school to a local college and 18 years old started university in West London where I combined my love and talent in the sciences with my sporting passions to study Sport Rehabilitation with Health and Human Biology and trained as a Sports Injury Rehabilitator. Following graduation, I started a career in sports injury prevention, treatment, and management that took me from working for local rugby clubs, to running the fitness facility at a five-star hotel that was also the training venue for an international sports team. Here I had opportunities to work with elite sportsmen, coaches, Hollywood movie stars whilst completing my Masters Degree in Sports Science and Medicine. The successful completion of this degree programme, combined with my lifelong passion for teaching, meant that my career progressed, moving me out of front line injury management to an academic role at a University in West England, where I taught for two years.

During this time I met a man called 'Pete,' and we started a relationship. This relationship was punctuated with infidelity on his part, and two years after my teaching role began, I sought to leave the area and move closer to my family to continue my academic career at another University. Pete followed me, and against my better judgement we rekindled our relationship. I had been at my new institution three months teaching injury rehabilitation when, in January 2010, I broke my wrist on day one of a snowboarding trip. The irony of their sports injuries lecturer being in plaster for 10 months following this break was not lost on my students! I was finally given the 'all clear' for this wrist break in early December 2010. Three weeks later, an audible and palpable 'clunk' started my journey towards a diagnosis of osteoporosis at the age of 33.

It was the December of 2010 and 'Pete,' and I were at my parent's house for a pre-Christmas visit. My relationship with Pete was still not a happy one, but on this occasion, we were getting on well, and he had pinned me down with his chin on my

ribs as he tickled me. As he pushed his chin down something gave way, and the resultant clunk caused us both to stop immediately and him to jump back in shock. There was no pain. *What on earth had just happened?!* We passed it off as nothing of any concern and carried on with our day with my parents. Back home, the next day I noticed a lump on the left-hand side of my breastbone and the area started to ache. Over the next 48 hours, it became more and more difficult to complete daily tasks without it feeling like two ends of bone in my chest were rubbing together. It felt like things were moving where they shouldn't be. It was such a peculiar sensation. Now, one week later and the week before Christmas, I was sitting on the floor wrapping presents but found myself unable to even reach forward to get the sellotape due to the pain and 'catching' feeling in my chest. I had to hold my hand to my chest to try and stabilise myself before I could move my arm. At its worst, I had to log roll myself out of bed in the morning. I figured rather than just having bruised myself; perhaps I had subluxed a rib. The now obvious lump that was on my rib cage was near to where the cartilage of the breastbone has attachments to the ribs so a subluxation seemed quite plausible to me. Either way, the pain and lump were not going away so after Christmas was out of the way I decided to seek the help of a friend of mine.

Having worked treating musculoskeletal sports injuries for 10-years and being an Academic in the field, I had built up quite a nice network of friends who could help me out in such situations. One such friend, 'Nick', was a senior chiropractor at a chiropractic training college. I explained what had happened and that I thought I needed a little manipulation to get my rib re-situated. He invited me to make an appointment at the student teaching clinic, and within 48 hours I was on a treatment couch, having a physical examination with a final year chiropractic student, prior to what I thought would be a routine rib relocation.

As with all treatments, my student practitioner went out to gain agreement from the teaching team to continue with the proposed treatment. Knowing it was me in the treatment room, Nick came in, and having read my interns notes, asked to re-examine me. He felt my ribs and frowned. He stood back, observed the hard lump

that was now a permanent feature on the left-hand side of my sternum and he did not look happy. He was concerned that the lump was just a little too far away from my breastbone to be a dislocated rib so asked if I had time to stay for an x-ray. He wanted to see exactly how the rib had situated itself. Radiography was available on-site, so we walked to its location, chatting happily as we did so, exchanging stories about family Christmases and thoughts on the new academic term that was about to be upon us. The x-ray itself was quick, and we continued our chat as the image appeared on the screen next to me. In that moment, my life course started to divert in a way that I had never imagined possible.

An unexpected x-ray result – January 2011

We all stopped talking. I had never seen a rib X-ray with such obvious rib breaks on it. In black and white was an image confirming that I had broken my ribs so severely that each of four broken ends of bone had all crossed over each other. The lump on my chest was now easier to explain. I just could not understand it though. Each of us in the room had enough experience in musculoskeletal health to know that this should not have happened from the force I was subjected to while being tickled. The mood in the room had changed. Nick broke the silence and started to speak of possible reasons as to why my ribs were so fragile. He gently talked me through, but actively played down the possibility, that I might have had a bone tumour (benign or otherwise) that could have weakened that boney area, or for some women, usually far older though, osteoporosis was a cause of these low trauma *fragility* fractures. With the college having the facilities to assess and rule out the latter and a General Practitioner referral needed to investigate the former, the conversation moved towards looking further into my bone density.

I can honestly say that I had never given my bone density a second thought up until this point. As far as I was concerned bone density and osteoporosis were only ever a concern for older postmenopausal women. The word *osteoporosis* for me conjured up the imagery of pictures in my university textbooks showing weakened bone structures. It caused me to think of shrinking, little old ladies with stoops who fell over and broke their hips. It certainly wasn't a viable option in my mind for the

cause of my rib breaks, which I was now just putting down to bad luck and my boyfriend applying more force than either of us recollected.

Since the clinic had a calcaneal bone densitometer (a way of assessing my bone density through the assessment of my heel bone), they arranged an appointment for a few days later. I was warned that the heel scan was not deemed overly accurate, but it would still be a useful thing to do. For 72 hours and with my options being bone tumour or osteoporosis, I started to research both potential diagnoses online. The potential to have a bone tumour seemed quite scary, but in my gut, I knew it wasn't that. The only information I found on osteoporosis in these early searches were overviews of causes (menopause, old age etc) and preventative measures (staying active, eating dairy etc) and since none of the information I found related to me and my situation I was of the frame of mind that the breaks were just pure bad luck and I probably should have just ignored it…rather than be led by my personal / professional curiosity as to what was going on. But one thought did prey on my mind in this period before my heel scan.
This was actually my second low trauma fracture in the space of 11 months.

Revisiting my first fracture - January 2010

In January 2010, I was on my first run down the slopes of Austria on a snowboarding holiday with Pete. I was facing up the mountain whilst turning and brushed my fingers against the snow. I felt a pop in my left wrist that I can only liken to breaking a piece of chocolate off a long bar. By the time I got to the bottom of the run my wrist was excruciating. I had my wrist guards in my pocket but in the excitement of the first day and I had forgotten to put them on whilst heading up the mountain in the gondola. I was in so much pain I struggled to take my mitten off. But I couldn't have broken it! I hadn't even fallen over! I tried to continue for the day but couldn't push myself up off the snow and so during the final half hour of the lifts working I said to Pete that I thought I had broken it and needed to go to hospital. His reply was that if I needed to go to hospital I should go, but he was going to go up the mountain one more time and call me later to see how I was getting on. The shop at the bottom of the slope called the ambulance and off I went on my own.

The advantage of breaking a bone whilst on a snow sports holiday is that every trauma department near the resort is so accustomed to boney injuries that I was in and x-rayed within 15 minutes of arriving! Five minutes after that I was being told that I had a complete fracture of my scaphoid and was then placed in a back slab, given some strong pain-killers and told to get re-x-rayed as soon as I returned to the UK. This was so annoying. I wanted to be the cool snowboarding chick, not the 'Girl that Broke her Wrist on Day One!' Thanks to the painkillers, a large man's mitten to cover my cast (and fear of Pete getting angry with me for spoiling his holiday), I carried on snowboarding for the rest of the trip. I was slow. Scared to fall over. Struggled to get up off the snow as I couldn't use my left arm to push up. It was so sore. I had to have help getting dressed and undressed. I couldn't sleep due to the pain and weight of the cast, but I also wanted to try and enjoy the holiday so the week passed without further incident and we returned to the UK. The back-slab by this point was so uncomfortable that I went straight to A&E for an x-ray and re-plaster. The full thickness fracture was confirmed with the words *'Well you have well and truly done your scaphoid!'*

A week later I returned to hospital for my first fracture clinic appointment. My appointment was with a specialist physiotherapist, and I was told that I would be in plaster for 6 weeks and then it should all be fine. I wanted to believe her, but I knew from my training that a scaphoid fracture (particularly a full thickness one) is really hard to heal and it would be unusual for it to heal in six weeks. But I trusted her. I was the patient not the practitioner, and I wanted to believe six weeks would be enough. Six weeks came and went, and I was put in another cast for another six weeks. Then another and then another. CT scans. MRIs. Each confirming that full healing had not yet occurred and I needed to stay immobilised for longer. This was tough. Mentally tough. Physically tough. I couldn't grip, I couldn't lift weights, I couldn't shower without my arm above my head in a bag, and I was now 6 months in plaster and still, it ached and still it wasn't healing. Finally, the frustration and upset was too much, and I sent a letter of complaint to the Trust that I should never have been told a scaphoid fracture would heal in six weeks. The result of this was that I saw the main upper limb orthopaedic surgeon at the local hospital. He asked why I

hadn't chosen to have my wrist surgically fixed and I replied that that had never been presented as an option. He said we should now make the *'best of a bad situation'* so he recommended an operation to see what was going on in my wrist. It was now September and having spent nine months in plaster I was booked in for day surgery.

I woke to the blood pressure cuff inflating on my arm and saw my hand heavily bandaged and hanging from a drip holder! I don't know what I was expecting, but it wasn't a huge bandaged lobster claw in front of me. It was so sore. So uncomfortable.

I had had three areas of non-union within the fracture site so they agitated them to promote healing and removed a cyst in the scapholunate ligament. After another two weeks and a post-operative follow up, I was finally (10 months after the initial break) free from plaster. It took another two months to regain full use of my wrist, and in the first week of December 2010, I had a final MRI to confirm all was now well.

It was three weeks after this MRI that I experienced my rib injury. Once I saw the rib breaks, there on the x-ray, part of me honestly couldn't take anymore of broken bones, scans, pain and wondering about healing. Yet here I was again. Fractured and increasingly despondent.

Calcaneal Scan Results - February 2011

I had to wait three days for my heel scan appointment and then returned the next day for the results. The scan itself was over in seconds. Non-invasive, no claustrophobic tubes (like the MRIs I had spent time in the year before). It all just seemed very easy and passed without any great attention from myself. I really was not that worried when I walked in to get my results but as I sat there waiting to be called through I started to notice I was getting nervous and felt quite alone. I noticed the darkness and coldness of the room my intern and I went into, to meet the senior clinician who had my results. Sitting at a desk, with her back to me as we walked in, was the woman who I was soon to find was completely devoid of any

aspect of empathy or compassion. To this day I still don't know if I can forgive her for how she conducted the next five minutes of my life...the interaction that would change my life forever.

I sat down and was immediately confronted with the question '*Now tell me – what made you want to have a scan?'* It felt accusatory. Maybe this was all going to be ok after all!!! It felt in this moment that I was just going to be reprimanded for wasting their time and told to go away! I replied that I had broken my wrist the year before, and now had broken two ribs, so Nick had suggested I have a scan.
There was an uncomfortable silence. "*Well, I can tell you I am glad you did, as this is the worst result I have seen all day and if we don't deal with this now…well you will die from osteoporosis. You are between osteopenia and osteoporosis.'*

Has this actually just happened? Has someone just told me I have osteoporosis by saying I could die?! I had never in my professional training come across the concept that people with osteoporosis could die from it? Fracture, yes. But die……? This was starting to get too much. As I was trying to process these words, the next verbal assault came. '*The first thing I can tell you is you need to start eating properly and get some more meat on your bones.*' Ok,…now I was on the defensive. *'Excuse me? I do eat properly, have always eaten properly and cannot fit my mother's wedding dress as she was slimmer than me at my age!'* Is this woman assuming I have an eating disorder just because I am young and have low bone density? How on earth can another woman be so cold in this situation??

'Now tell me about exercise – do you do any? Please tell me you don't go out running for hours and hours?' Just stop! This is the most horrific experience I have ever been involved in! You've just told me I could die from osteoporosis, you've accused me of having an eating disorder, and now you are judging my exercise preferences??!! *'No, if I run I lose too much weight, so I go to the gym and lift weights.'* 'Good' she replied. *'Now we will write to your GP and see what they suggest.'*
Her parting words to my intern were that I should *'be treated with kid gloves'* and I left the room with the familiar feeling of trying not to cry. My only companion

throughout that appointment and in the moments after was my rage at how awful that woman was. I couldn't help but think that no one should ever be in a position of delivering news, such as this woman had just told me, if they cannot connect within another person on any sort of humanistic level. It was just too cruel and made the news ten times worse.

I walked to my car, outside the chiropractic college and sat quietly, feeling very alone...I had just been told I had osteoporosis. I had done nothing but fight back tears since I was 13 years old. I had put on a front and pretended that I was okay on so many occasions, but in this moment of shock, confusion, panic, and fear, I was not okay, and this was just too much. The bullying at school was bearable because outside of school hours I was happy, I was at home. Living with Pete was bearable because I could hide at work and not have to be in the house…But this news was too much. There was no escaping from this. All I could picture were the images of porous bones that I had seen in all the textbooks throughout my career. I was a lattice of air and fragility. I phoned my best friend Dave, and straight away told him I had osteoporosis… The line went quiet, and then through a strained voice, he said '*…..Oh love……'*.

His reaction hit me like a punch to my stomach – Oh my god I had said the words out loud, and this was actually happening. I actually had osteoporosis. Please, someone, take it back. Please take the words back. I couldn't have this. I started to panic. I genuinely didn't even know how to begin processing this information. I chatted with Dave for a while, and he promised me it would be okay and he would come with me to any further appointments so I didn't have to go alone. Dave and I had been friends for 10 years. We had also dated during that time, and I considered him at that time to be my guardian angel on earth. Being thirty years my senior we both knew there was no future in the dating aspect of our relationship but it didn't stop us from being incredibly close, and he was naturally the first person I wanted to call after I came out of that clinic experience.

Twenty minutes later and I had to be in a classroom teaching. Pete was in a similar field of work to me and so was covering my lesson as a guest speaker so that I could

go to the clinic appointment. As I walked into the classroom, the students were doing practical activities. I went up to Pete and said '*So, I have osteoporosis*.' He laughed and said '*Oh shit!*' But that was the extent of his concern at that moment. I, however, felt like I was drowning. I felt pushed under the water, seeing the lights of normality flickering above me, but I couldn't reach them, and I couldn't breathe.

Sitting in the corridor until the lesson finished, the feeling of suffocation, drowning, panic became overwhelming, and I started to cry once more. I didn't want a future where I was to be unwell. I didn't want the future I was going to have. I didn't want to fracture, to be in pain, to stoop, to become old before my time. Why couldn't I just be normal? Why, yet again, did I have to face something utterly horrendous? Why couldn't I be one of those people who just went through life never really experiencing the depths of sorrow that I have experienced...All I knew in that moment was that I didn't want this and I couldn't see a way I would ever be happy again with this overwhelming my life from this point forwards.

I booked to see my GP and took my calcaneal results with me. The doctor had received a letter from the clinic, and we agreed it would be useful to have a full DEXA scan in order to establish a more accurate value for my bone mineral density. But I did not fulfil enough of the criteria for the request for a scan to be agreed by radiology. I had never taken glucocorticosteroids. I had never had anorexia or bulimia. I was not coeliac or an alcoholic, and I had regular menstruation and so was premenopausal. In no way was I indicated to have a scan for osteoporosis. I was just a young woman with what appeared at this point to be dramatically reduced bone density yet it would seem I could not have the necessary scan to establish a true account of the extent of my condition. The GP said that he would call radiology and finally it was agreed that I could have a scan due to my calcaneal result and history of low body mass. I had always been tall but was incredibly slim as a child and adolescent. The GP thought that this, combined with the related late onset of menses, might be enough to convince them, and it was.

On March 28th, 2011, 14 months after my first low trauma fracture, I was sitting in the radiology reception of my local hospital, waiting for my name to be called. I still

held on to some hope that the calcaneal scan had been inaccurate. People in casts, who had broken limbs and were awaiting x-rays, surrounded me. That should have been me. I should have been sat there with a cast having broken a limb doing something really cool…snowboarding (ok I've done that!), mountain biking, jet skiing, anything other than what I was actually there for. I was sitting in the area designated for the DEXA scan, with little old ladies for company. I stuck out like a sore thumb. The dear woman to my right was in a wheel chair and had a stoop. The lady opposite me had her husband with her and was clutching her appointment letter and his hand with what appeared to me to be a mixture of nervousness and need. Both were very much older than my parents. Yet here I was. Aged just 33, in a work tracksuit, trainers on. I had been to the gym that morning lifting weights heavier than I was, yet I found myself on the same journey as women over double my age. I would have done anything to have been able to move to the other side of that blue line on the floor, to go back to where I belonged, back to the accidental fracture group rather than the fragile and brittle group.

Waiting for the DEXA scan results – April 2011

As I waited for my DEXA results, I felt as if I was in no man's land. I had been desperately seeking information on osteoporosis and how I might have ended up with this potential condition, from the moment the word was uttered after my chest x-ray. When talking with others, I found that I choose my words very carefully and never actually use the word osteoporosis. I call it a *condition*. I was being investigated for a 'bone condition.' For me 'condition' implied that it was temporary and that something could be done about it. If I lost that mind-set for one second I found myself in tears.

I found that I also couldn't just sit there and internalise the situation. I felt so angry that this was happening. I didn't want any other young women to have to go through this process. It was the most horrific thing I had ever been through, and I had been through a lot, but I felt I had to be able to stop this from happening to someone else. Everything I had read from my research so far supported the fact that I was potentially in this situation because of a combination of factors I had

experienced in my teenage years. I had read that most bone was laid down during one's teenage years. I had read that low body weight, late onset of periods and depression were potential factors in not reaching one's peak bone mass. I started to build my own research-based narrative on how I could have ended up in this position and it all started to point to my experiences at school. Every time I thought I had processed those years something else sucked me back there. As if struggling with anxiety for 20 years hadn't been enough…I felt at that time as if the bullies really had won now….

In an attempt to externalise my thoughts and the situation, I couldn't help but think that if I could help others or raise awareness somehow, then at least some good would have come out of this. Even if the results of my DEXA scan were actually normal for my age, I felt this experience had opened my eyes to the potential impact teenage experiences could have on ones later health, so, as I waited for my scan results, I decide to start a blog. I had to take action somehow. Even if one other girl read it and realised the potential impact that their teenage experiences on their bone health then it has been worth sharing my experiences. 'Activism' was my new coping strategy.

I had my scan and instantly regretted knowing anything about musculoskeletal health. Whilst the radiographer wouldn't tell me my result and cheerily said that a letter would be sent to my GP with the results, I could see the computer screen in front of her. I could see the graph. I could see the stripes of green, amber, and red and I was sure I could see an 'X' within the red section. Is that where I was? Was that 'X' basically telling me that there is no going back now? Clearly, I didn't know for sure, and the radiographer caught my eyes on the screen and said the results needed to be processed before they were sent out. I hoped at that point that maybe I was wrong. I tried to be positive, but I had a nagging feeling I had just seen the reality of my current situation.

Over the next two weeks, my main outlet for my concerns and fears was my blog. I ensured that was anonymous – I didn't want people to know it was me that was

writing. I introduced the blog as being for education about bone health in order for people to consider how their present circumstances might affect their bone health in the future. I found humour was the easiest way to present my story, to make it accessible to others, without it being a long woeful tale that no one would want to read. The blog was a focus, I felt proactive, I was researching and writing up information for others to learn from. I guess I had reverted to my main roles in life of being an educator and a healer. I found those roles gave me purpose and meaning in this turbulent time and I used the humour to lift my own spirits and play down my fears.

The results come in – April 2011

I was so scared counting down the days until I returned to the doctor to get my DEXA scan result. Up until then there had been doubt and hope. After results day I had FACT to deal with. The consequences of that fact were too big to think about and made me cry if ever I allowed them to penetrate my thoughts for too long. I was trying to reframe the experience as a wake-up call for looking after my body and myself. If I could just convince myself that osteoporosis was a transient 'condition' and nothing else then I could do something about it and maximize my skeleton's potential. In a few years' time I could look back and feel proud that I once had osteoporosis but I 'fixed' it and was now fine.

During that weeklong wait I anchored myself by returning to my sports medicine training and *science.* I knew if I wanted to increase my bone density I needed to load my skeleton. I needed to take ownership and start regularly training in the gym again. Using my University level access to research papers I started to research the best exercises for increasing bone density. What I found though was a mass of conflicting advice that resulted in a feeling of frustration. I couldn't understand how there could be so many studies published that were using exercises that any sports injury professional could tell you would not result in enough direct load to increase bone density. A huge number of studies focused on balance training with the premise being if the 'fragile' people don't fall over, then they won't break anything!

But I was a young woman...I didn't have balance issues! Was I really so alone in this process that there was no research available to address MY needs?

I decided to follow my own programme and returned to the gym. A week later I had completed three strength-training sessions and went to see my GP to get my official DEXA results. On my doctor's desk was a prescription for bisphosphonates, calcium and vitamin D. I had osteoporosis. He hadn't said the words yet but if he had already printed that prescription then I couldn't see how this could have any other outcome. I felt my eyes prickle before he said a word. Yes, I had osteoporosis. My GP admitted he had never come across a young woman with osteoporosis before. '*I assume you want to know what we are going to do about this?'* he asked. I had just been told I had the spine of a 60 year old, and the hips of an 80 year old. It was now 'officially' official. As I sat there and listened to his question I couldn't help but reply *'No!'*. I wanted to know how on earth I had got it in the first place. I certainly wasn't just going to start taking medication I had read such bad things about, before gaining a comprehensive understanding of why my bones were as weak as they were. I asked the GP directly *'Why have I got osteoporosis?'* He didn't know. I asked if there were any more tests we could do to explore potential causes. He said we could try a full blood screen and see if anything came up. As we worked through my questions it became clear my doctor had no clue what to do with me and I gradually lost faith in him. I couldn't reconcile why I was suggesting to him how we might move forward to find the cause. All he wanted to do was medicate me in the same way he would an older woman.

My full blood test results came in within a few days and I was showing two 'abnormal' blood results. Firstly, I was anaemic. I politely pointed out to my doctor that if he looked at my medical history he would see I carried the beta-thalassemia trait (as do my mother and brother) so (due to the resultant small red blood cell size) we always show up as anaemic but never are. He needed to look at the ferratin result instead. He paused, apologised and said yes I was actually not anaemic at all. He then told me that I presented with an elevated parathyroid hormone result. The GP found this 'quite interesting.' He had looked it up and parathyroid hormone was

related to bone density but as he was talking about maybe retesting in a few weeks I had already made up my mind I needed to feel like I was taking action now, not wasting time exploring options. Every day that passed was another day where I didn't know why my bones were so weak and I felt I was losing the precious time I had to fix them.

My frustrations resulted in tears. Why couldn't anyone just tell me the answer and look after me? Why did I have to fight this all on my own? I spent the next two hours alone at home, curled up on the sofa, feeling what I can only describe as grief for the loss of my hope for a happy life. I had to be proactive. I had to feel like I had some element of control. I decided to bite the bullet in terms of cost and use my private health insurance. I found the highest rated parathyroid consultant in the country and within 30 minutes was back on the phone to my GP to ask for a referral. I couldn't waste any more time in a system in which I had no faith. The GP agreed to refer me and in that moment I felt calmer.

The test result also prompted more research activity on my part and I started to research parathyroid and its effect on bone density. I was excited by what I found. There was a strong link between parathyroid function and osteoporosis but the resultant osteoporosis was only temporary! Parathyroid hormone was responsible for leaching calcium, from its reservoirs in bone, back into the blood stream. Too much of this hormone could be attributed to a condition called hyperparathyroidism. Hyperparathyroidism symptoms included excessive fatigue (check) and depression (check). Also from what I had read, as elevated levels of this hormone meant that the individual had elevated levels of Calcium in their bloodstream, those with hyperparathyroidism should never take a calcium supplement as it makes you feel sick (basically calcium overload) and should NEVER take bisphosphonates as they reduce your BMD further! I felt as if I had struck gold! Maybe this was it?! Was this was the cause I could anchor my situation to, to give it meaning, to help me process why I had osteoporosis? I found myself getting over excited and knew the next stage was to have more blood tests but for me, and my inquisitive mindset, it also raised the question, *'Should parathyroid blood tests become a standard protocol, before GPs ever tell patients to take calcium and bisphosphonates, just in case*

parathyroidism is the cause of their low bone density?' The standard prescription for a low DEXA result indicating low bone density is the exact opposite of what those with osteoporosis due to hyperparathyroidism should be doing. What made me most excited about this blood result was that hyperparathyroidism was reversible. If the overactive parathyroid was dealt with then bone formation restarted and depression symptoms disappeared. Could this hormone have been the key to everything? It certainly would have explained my predisposition for depression.

I was flying high on this new line of enquiry. I woke up the next morning with an unexpectedly proactive mindset. As the day went on I still wept if I allowed myself to think about the potential implications of osteoporosis for my future but I tried to reframe things to feel quite lucky to know that I had it. I could do something about it. I couldn't help but think of all those women who experienced eating disorders, or who were on a quest for 'size zero', or who were exercising excessively, or avoided dairy because they thought it was fattening. All of those women with stressful jobs who then added more stress to their body by adding caffeine… I had never done any of those things but had through my research found that they were all risk factors for osteoporosis. None of these women would have known their bone health status as DEXA scans were not freely offered to premenopausal women. They might only get a scan if they started to fracture postmenopausally. I was finding I was getting more and more frustrated at what I perceived to be a focus within literature and in practice, on cure rather than prevention. I was pondering the cost effectiveness of scanning women in their 20s if they present with risk factors, rather than just leave them until they start to fracture later in life.

I was naturally slight, I exercised, I ate well yet at 33 I had osteoporosis. I couldn't help but imagine how many women were walking around in a far worse state than me but didn't have a clue about it. By the time they find out they would have lost the chance to do anything about it. I was actually, really lucky. I was lucky because I was only 33. I was educated about the human body and I was lucky because my inquisitive mind, combined with my job, meant that I had by this point pretty much completed a full literature search on osteoporosis treatment. I was lucky because

the people I have worked with/met in my life so far meant that I was able to fire emails asking for advice off to the Head of Research at the British Olympic Association Medical Institute for example. I was lucky because I had a pretty full understanding of the mechanics of the human body, of exercise and the principle of bone formation and so was already on week two of my training programme designed to stress my skeleton and promote adaptive bone growth.

By the end of April 2011, I had been *osteoporotic* for 3 weeks and managed to get a few days away in Portugal with Dave. I tried to make light of my bone situation and tell friends and family I was popping away to top up my vitamin D. The much-needed break and subsequent hours spent on the sun lounger led to too much time to think about my situation and one night I broke down. I could only muster the energy to try and remain proactive and positive for a certain amount of time before I would need to just let all my fears out and cry. The trigger for this break down was the terminology the GP had used when giving me my results. It kept praying on my mind. I was fine all the while I was thinking in terms of T-scores and Z-scores, everything seemed quite manageable. Those numbers gave me a baseline measure and I was just going to make sure that I improved on it in my next scan. When I was told what 'age' my bones were however, things changed. There was a massive difference for me between a ‘score’ and an 'age'. Tell me my T-score is -1.7 and I am ok. Tell me I have the spine of a 60-year-old when I am aged 33 and I am NOT ok. It conjured up such a visual image. I was ageing prematurely. If I had the skeleton of a 60-year-old at this point, what would I be like when I was 60? I would have the body of a 90-year-old? My grandmother is in her 90s. She is bed bound. She has osteoporosis. Her lower spine has crumbled to such an extent (exacerbated by a fall) that she had health issues that I do not wish to articulate here, as they are both embarrassing and upsetting for her. Was this my future? Was this what I would be like by 60? If so I knew I didn’t want to be here to experience it.

As always the upset passed after about 24 hours and with the completion of the holiday I returned to the UK. I was back at work, training hard and still information gathering. I also asked to see my GP for a follow up appointment. I had to initiate it

but just wanted to talk some more things through before my consultant appointment in a few days' time. I applaud my Doctor's honesty in that appointment, but no one who has received a diagnosis needs their GP to turn around to them and say *'Well I'm a bit stumped to be honest. None of my patients in your position are younger than 60!'* He was still really keen for me to start taking the bisphosphonates but I really wasn't sure I wanted to and I definitely wasn't going to until I had had my parathyroid checked fully. I had heard and read horrific things about stomach ulcers and osteonecrosis of the jaw from osteoporosis medication and I really didn't want to take medication if there was something non-pharmaceutical I could do. We also hadn't yet identified a cause. I was taking vitamin D and calcium, I was eating really well and loading my skeleton through weight training, but my GP was really quite insistent that the only way to get me 'back to normal' was through pharmaceuticals. I tried to argue the point that if you look at the research studies on exercise and increases in bone density, some were really poorly designed, so no wonder they saw no improvements but physiological we know that if we place load on bones they react and respond by getting 'stronger.' My refusal to start taking the bisphosphonates led my GP to tell me he was going to write to an endocrinologist for advice and he would call me. I already knew that after this appointment there was no point in talking to my GP anymore. At this point, only a month after diagnosis I knew more than him about my condition and we were both wasting an appointment someone else might need.

I was feeling quite strong as I left this appointment. I felt I was being proactive in exploring the cause of my situation and that was important to me. My positivity was short-lived when, within days, I bumped into a physiotherapy friend of mine. He asked how I was. I was starting to feel more confident in telling others about my condition and what I was going through, so I told him. He then proceeded to tell me the exact opposite of everything I thought I had got straight in my mind as to what I should be doing with regard to exercise and training. All my GP wanted me to do was take bisphosphonates. My physiotherapy friend and others I had spoken to said to avoid them like the plague. Research stated the treatment for osteoporosis was to take vitamin D3 and calcium in conjunction with bisphosphonates but when I read

the supplement leaflets they said, under Interactions with Other Medicines '…may reduce the absorption of bisphosphonates'. Research recommended to lift heavy weights, but my physio friend said I should do long slow duration weighted walking like hiking or Nordic walking. Some research said to have a high fat diet but my friend said that was bad news and to reduce fats. The common theme was the need to reduce stress, as it was cortisol, the stress hormone, that increased the breakdown of bone…yet this was one of the most stressful periods of my life so far! I was confused, scared, frustrated, panicked, so stressed and generally overwhelmed by the fact I have been left to deal with all of this on my own. I honestly couldn't believe that you are given a diagnosis of osteoporosis at the age of 33 and are then left on your own to try and find answers. No follow up, unless requested by me, no referral to a consultant, no guidance, no advice, no drive to find out the cause of the condition unless you kick up a stink with your GP like I did.

Seeking local support and education – May 2011 - 1 month since diagnosis

A week later marked the start of May 2011, just over one month since diagnosis. The day before my consultant appointment I decided to attend an osteoporosis awareness event for the local osteoporosis support group. Ultimately I wanted to ask a consultant about screening younger women with risk factors and one was attending this event, along with a physiotherapist and dietician. With a specific research question in mind I hadn't expected to get teary in the car park but on arrival I suddenly realised I was going to be faced with a room full of my future. Little grey haired old ladies, some in wheel chairs, two on oxygen, were filling a conference room in a local hotel. Four mobility scooters were parked outside and as I walked in to register I was asked if I was attending with my grandmother.

As the session went on and speakers presented their elements of the programme, I found that my frustration and anger was superseding my upset. I was honestly taken aback by some of the advice the audience was being given. The dietician was telling everyone to drink skimmed milk, avoid protein as we *"didn't want to be body*

builders" and we were told to eat fortified cereal, margarine, to add dried skimmed milk powder to our meals, snack on cereal bars and that it was ok to be four-five stone overweight as the "*fat protects your bones when you fall"*.

I just couldn't comprehend what I was hearing. This was so unfair on the audience. We were all there as we were desperate to improve our current position. If people weren't self-educated in this area they would follow everything the dietician was saying and their health outcome might be affected. It just was not fair on these people. Why weren't we told about the benefits of whole foods, about natural sources of calcium, about how to avoid large ranges in blood sugar and told the long-term benefits of eating well? We were told that the body mass index was a really useful tool for assessing if you are overweight. But anyone in the health industry knows that this just isn't true. Why were these so called 'experts' not up to date on what they are saying? They are playing with the health of the 100 or so people attending the event and it just was not fair on them. They deserved better. They deserved up to date research at the very least.

The physiotherapists proceeded to tell us that we should do bicep curls with bean cans, to practise standing on one leg and to avoid impact exercise at all costs. Of course I appreciated that for some in the audience these exercises were completely appropriate. They would not, however, improve their osteoporosis. The exercises would help them develop balance to avoid falling and their potential to fracture with that fall, but they would not improve their bone density. One woman in the audience said she was the Ladies Captain at her local golf club so should she stop playing golf? The physiotherapists ummd and errr-d and said that any rotation exercises were best avoided. At least 50% of the ladies in the audience looked incredibly active and were involved in sports such as badminton, bowls and golf or went to the gym for personal training. The active, early retirement generation with osteoporosis were told not to do sit ups or skip. How were they supposed to get out of bed in the morning if they were now banned from flexing their spines for fear of fracture? All of this information was so unfair on those active women whose involvement in their sports was their anchor to a normal active life despite their

bone density. Inactivity was being promoted and would never have a good health outcome in the long term.

The consultant reiterated something that I had come across in my information gathering that had baffled me at the time of reading. His explanation was clear. You take bisphosphonates to slow down bone turnover and therefore try and strengthen your bones just in case you fall. Osteoporosis means that if you do fall you are at greater risk than the average person of breaking a bone. However the term 'risk' means that it may actually never happen but one of the side effects of bisphosphonates is that it decreases your rate of bone healing…So, if you do fall, and you do happen to fracture, you are less likely to heal in a timely way because your bone medication has slowed healing and this can lead to severe complications. Maybe we should just acknowledge the risk, avoid bisphosphonates, avoid activities where we might break something and then if you are unfortunate enough to fracture at least you have half a chance of healing quickly compared to those on bisphosphonates?!

At this point in my journey I was getting so frustrated. Contradictory information was everywhere. It was so hard to have confidence in any one school of thought or any one individual. I was only doing basic literature searches at work and I was finding information on osteoporosis that just wasn't being used in the public domain and I didn't understand why. Why did I, only 4 weeks post diagnosis know more about the guidelines on this condition than those who are working with those affected?

A Trip to London - May 2011 – Five weeks post diagnosis

It was the day of my appointment in London with the Consultant Endocrinologist who was a specialist in parathyroid function. As he promised on that first day when I told him the news of my diagnosis, my best friend Dave made sure he was free to come with me (my boyfriend hadn't offered to) so we booked a hotel and made a trip of it. The private hospital we went to was like a hotel in Dubai. Marble floors, a long shiny reception desk, white leather sofa seating areas as we waited to be

escorted through to see the consultants … It certainly wasn't the fracture clinic in my local NHS hospital that's for sure. The man I saw was eccentric, kind, funny, baffled by my case and presented me with three main lines of investigation. I already liked him. He knew what he was talking about.

Firstly, it could be that I was going through early menopause and the implication of this would be that I could never have children...I cried. At least this news was delivered in a far more empathetic way than my original diagnosis but I could see Dave tear up at the gravity of that news. I tried to hold it together. Secondly, I could have a parathyroid tumour but on physical examination my parathyroid did not appear to be enlarged. The consultant wanted to carry out blood tests to ascertain the likelihood of the first two scenarios being linked to my bone health. He commented on my history of low body weight and late onset of menses being a potential contributing factor in my osteoporosis but his main question mark over the cause of my condition was to investigate my history of taking Citalopram. He left Dave and I alone while he went to ask his head pharmacist if there was any known link between Citalopram use (a Selective Serotonin Reuptake Inhibitor – SSRI used to treat anxiety and depression) and bone density. Ten minutes later the pharmacist had confirmed that yes, SSRIs were linked with reduced bone density especially in the hips (my area of most concern).

I started to process this information. All I had wanted since the diagnostic process had started, was a cause of my osteoporosis. If my citalopram use had caused my osteoporosis then all of the sorrow I had experienced in my life as a direct result of that day in Year 9 at school, when I saw the signed note in a classmate's pencil case saying *'I promise not to talk to Joey Hawkes'* was now ingrained in my skeleton...A permanent reminder of all of the tears I had shed in the last 20 years, with each tear slowly corroding my bones to the point where I was now a shadow of what I should have been. And they had no idea. The bullies had absolutely no idea, as they happily lived their lives, of the scars they had left within me. I wanted to contact them. I want to say I hope it was worth it. I hope that piece of paper that it turns out everyone in the class had and to this day I still have no idea why, made you feel how

you wanted it to. Because it made me feel like I was unlovable, that no one would ever want to be my friend and I felt alone.

Sitting in the car crying after my initial heel scan, I felt the same loneliness. I felt it when I didn't know who to call with my bad news because I didn't want to call my Mum and Dad as I knew they would be sad – Just as I hadn't told them about the bullying for fear they would be upset on my behalf…or the abusive boyfriend. I felt it when I told that boyfriend my diagnosis and he smirked and said *'oh shit!*'; when I broke my wrist and went to the hospital alone; when I turned 30 and realised that I had struggled with the aftermath of bullying, the anxiety, the emetophobia, my perceived inability to make deep friendships, my poor self-confidence and the boyfriends who never quite loved me enough not to cheat on me (repeatedly), for over half of my lifetime.

That trip to London, that day was a defining moment in feeling like the bullies had well and truly won. I felt an empty loss that day that I just couldn't put in to words to describe. If this was all due to the Citalopram then 13 year old girls had caused my life to now feel as if I didn't want to be living it any more…

A Pause for Thought – Placing my Present in Relation to my Past

At this point in my journey I reflected a great deal on those years since school and the reasons I had been on Citalopram since I was 21 years old. I will visit the back-story to my Citalopram use at this point within this chapter as this was now appearing to be a key component in the main cause of my osteoporosis and caused me at the time to reflect a great deal on the triggers for my being prescribed the antidepressant. By the age of 33 I had been on Citalopram off and on for 12 years.

As mentioned previously, I am the middle child of two adoring parents who I can honestly say have always put their children first and still show such interest and love for all that we do. I am fiercely protective of my parents, a trait that I cannot attribute to any particular event or reason but is something that has been an element of my personality since childhood. I have always loved the closeness of

family. I am the one who loves to look through old family photos, who loves to keep in contact with extended family and who entertains when family are all brought together. I love our family traditions; the toast to absent friends at 2pm on Christmas Day; the receiving of a Hawkes signet ring on our 18th birthdays (Hawkes was my maiden name) makes me feel part of a large extended family hug whenever it is needed. I have an older sister who is 3 years my senior and a brother who is 4 years my junior. We now all live within four miles of each other with our own families.

My earliest memories are ones of granny cuddles and garden playing. We grew up in a small cottage in a beautiful village in Hampshire. My childhood was one of sunshine, playing in the field behind our house, getting told off for building hay bale houses in that field (!), church yard sledging in the snow of childhood winters and the continual wondering of whose birthday we usually go nutting on and whose is the blackberrying birthday! We usually missed both! I started a local independent primary school at age 3. With a birthday in September and mum having no luck settling me into playgroup in the village, I was always a year younger than my classmates and as a result I was offered the opportunity to repeat the final year of my primary schooling so that I would progress to senior school aged 11 rather than the 10 year old that I was. I chose to continue to senior school aged 10 and stay with my friends but I do often wonder whether my life would have turned out differently if I have just stayed on one more year and been with children my own age at senior school rather than with those a year older. I have no particularly emotive memories of my primary school years. We had carol concerts, I learnt the piano, in summer we had lessons under the big tree on the Headmasters lawn and we all ate together after saying grace with our classmates and took turns to tidy up the plates. At Christmas we were allowed to watch a film in the dining hall and on prize giving day, after our plays, the headmaster presented prizes wearing his graduation gown, a vision that has always stuck with me.

At primary school I had friends. We played. I had already started to show promise in hockey during PE uni-hoc lessons and was a happy young girl. I passed my entrance

exam to the local independent senior school, an all-girls convent school that my sister was already attending and progressed to senior school age 10 years old. I had a lovely time…for the first two years. I was a good student, talented and keen sports woman particularly in hockey, actively involved in drama, music and conscientious with my attitude to learning. There was never any incident of anyone not doing their homework at my school! The cultural norm was to try your best and do as the teachers said. Friendship groups changed and evolved but in the natural organic way that girls find their place in their social world and with only 18 pupils in my class and only 36 in the year we were all friendly to each other and maybe had a few stronger friends, usually from our prep schools. I was sporty, incredibly slim and starting to excel academically. In fact, all was well until I started in Year Nine. I was 12 and my classmates were 13 years old. At the start of this academic year I was voted by my peers to be Form Captain. I was so proud to be voted and took my role and responsibility seriously but this year at school turned into the start of one of the most pivotal periods in my life – It started a cascade of events that have changed me irreparably and haunt every aspect of my life.

To look over to a classmates desk and see a signed note saying *'I must not talk to Joey Hawkes'* was heartbreaking for my 12-year-old self and through the fact I have 'associative memory' it is an event I physiologically and emotionally re-live whenever I think about it. To this day I do not know what I did wrong to turn my classmates against me but they stopped talking to me and excluded me from activities. The experience of social exclusion that year led me to continually battle the feeling of wanting to cry but not wanting to let anyone see how upset I was. I would not let them see me cry. The feeling of tightness in my tummy, mouth closed, tears threatening to become visible, is one that has lived with me ever since and one I have had to battle in one form or another most days. Seeing that note was the catalyst for what has now been over 25 years of anxiety, phobias, low self-confidence and just a desire to be normal – to have friends, feel confident in myself and not have the mental clutter I continually have to keep at bay. But I did see that note, I did have to deal with social exclusion for the remainder of my schooling but I had no idea at the time how those three years would have such a lifelong

impact. That year coincided with my father losing his furniture business in the recession of the 1990's and so there was no way I was going to add to my parent's stress and upset but telling them what was happening between 8.45am and 3.45pm each day.

By the time I reached my final year in school aged 15 I still had no friends other than one girl in the year below me who was exactly the same age as me. The school day was filled with feelings of loneliness, wanting to cry but not wanting anyone to see me, wanting to understand what I had done to end up being so alone. I now know I got through it all by compartmentalizing. At school I just had to get through the day and not cry. But once in the car on the way home everything was ok again and that was the cycle I repeated for three years. There was a slow escalation in my inability to cope with the situation in which I found myself every day. In my final year I started to feel more and more sick. The nausea hit as we drove to school and by lunch I was so worried about feeling sick that I didn't want to eat my lunch, so would not eat for the duration of the school day and then tuck into my lunch box after school.

My final year at school – Constant anxiety, a fear of eating during the day – I shall leave the reader to determine whose legs were mine. (Faces cropped for anonymity).

The nausea led to me feeling as if I was going to be sick in lessons. The knot in my stomach from fighting tears would combine with hunger and make me start to panic and just want to leave the classroom to take a breather. I would excuse myself and go and hide in the toilets. On my own I didn't have to fight the tears and felt much better but then I became worried about walking back into the class. What would

people say? What would people think? So, I started staying out until the end of the lesson, and this progressed to staying out for the morning, I was developing a fear of anxiety, a fear of feeling nauseous, a fear of wanting to escape but having to be somewhere.

The most I ever told my parents was that I felt a bit sick quite often. Mum thought it might be a dairy allergy as I had always suffered with extreme rhinitis so we excluded milk and cheese from my diet for 3 years. It made no difference to how I felt at school but I never told my parents the extent of my extreme unhappiness. To this day they do not know the detail of what I went through, it would make them too sad to know. By the time I got to my GCSE exams aged 15, my fear of being trapped in a classroom had reached phobia status but again I tried to hide it from others. I left school with no friends and full-blown emetophobia.

I finally admitted my phobia to my parents in the September after my exams when I was due to start college. I ended up taking a year away from education after my GCSE's to try and work on overcoming my phobia. By the start of the next academic year, now aged 16, I felt I was ready to start my A-levels but would continue to struggle to manage my anxiety throughout my college and University education. The severity ebbed and flowed depending on circumstances. By the year 2000 I was finishing my second year and about to start my final year of University and had a particularly upsetting breakup from a boyfriend. It became obvious to my parents that I was no longer coping. Over that summer they encouraged me to go and talk to a doctor. After weeping through the consultation, I was prescribed a mild antidepressant, 10mg citalopram. Warned of side effects being sleepiness and feeling worse before feeling better, I took the first tablet and experienced nothing other than tiredness but this soon passed. Over the next few weeks the weeping slowly subsided. I started to feel better. I had no friends on my course so managed to find a roommate for the new academic year with a girl coming to do her PGCE and we found a nice two bedroom flat to share. I moved back up to Uni for my final year and something amazing had happened…an unexpected side effect of taking the citalopram was that my phobia had gone! I was free! I enjoyed lectures! I attended

everything! I could focus on what I was learning rather than looking for escape routes and just wanting the session to be over as quick as possible. I finally started to enjoy University and fulfill my potential. By the time our final grades came out I had graduated top of my year and was so proud of myself! What do they say? "Only those who have been truly fearful can be truly courageous," or something like that! By the time I graduated I felt better than I had in about 10 years!

Citalopram had changed my life. In the decade between leaving University and receiving my diagnosis, I had been taking citalopram off and on for about 7 of those years. Triggers for a relapse into emetophobia and the resultant return to citalopram were usually cheating boyfriends or particularly stressful work scenarios such as aggressive bosses. My most recent relationship with citalopram had been the longest continued prescription of 3 years. These were the three years before my diagnosis. The three years in which I was in a relationship with a man who was at first my prince charming and swiftly turned into a verbally and mentally abusive man who I did not have the strength or resources to leave. My emetophobia returned with the stress of that relationship and it was affecting my work. A lecturer in a University, I was finding excuses to not teach lessons and when in the classroom had, on more than one occasion, to make an excuse to stop the lesson half way through for fear of being sick. I decided to return to citalopram for the long term and finally accept that the drug enabled me to lead a normal life.

Final Questions Answered

My consultation with the Consultant Endocrinologist ended and Dave and I returned to my home town. It was a very quiet car journey. I thought about my life with citalopram, I thought about the bullies, I thought about early menopause and the potential I would not be able to have children…It was all consuming. Luckily I only had to wait 24 hours for my blood test results (such was the luxury of receiving private medical care). I was not having an early menopause and my bone markers were not showing a high rate of turnover. This meant that I was not losing bone but had stable but low bone density. Finally I did not have a parathyroid tumour as my parathyroid hormone levels were now back to normal. With the parathyroid now

ruled out as a cause the Endocrinology Consultant referred me to a Consultant in Osteoporosis he called a 'Super Specialist'. I felt one step closer to understanding my position and I finally felt I was being looked after. My referral letter to this second Consultant read *"I would very much appreciate it if you would see this delightful young woman, she really does need your advice and is quite sensible.' My mother's reply on reading that was that 'he clearly doesn't know you very well, does he!'*

My Mum and I went to London the following week for my appointment. We made sure we stayed to do a little shopping afterwards so that the day had a positive outcome no matter what the Consultant said. He was one of the loveliest people I have ever met and was clearly the man to go to if you want answers about bone density. He said that he thought one of the reasons I might have low bone density (combined with the previous factors that had been discussed such as low body weight, poor absorption during my teens, citalopram and anxiety) was my beta-thalassemia trait. He said he had often seen patients from Eastern Mediterrenean countries with osteoporosis and thinks that there might be something connecting the two. He reassured me that my bone marker activity was all normal and as such it is not that I was losing bone or degenerating, just that in my bone forming years I never made enough. As a result I only made about 70% of the peak bone mass that I had the potential for. He said that I should have another scan in 2 years time just to double check I have lost no further density and then just deal with it postmenopausally with Hormone Replacement Therapy (HRT). He said that unless you are in your 80s and living in a nursing home there is no need to take calcium or vitamin D and that no-one under the age of 70 should take bisphosphonates as not enough is known about them and their long term damage and side effects. He added that all a woman needs to avoid osteoporosis is oestrogen. I knew the answer already but had to ask the question just to be sure *'So is there any benefit to eating soya etc as they say it has phytoestrogens in it?" "Absolutely – eat away. Its great…..if you are a plant! Phytoestrogens are what plants need…Female oestrogen is what women need. HRT is what is needed when you reach the menopause and if anyone says to you 'oh but aren't female hormones dangerous?' say to them 'If they*

are so dangerous why do women out live men?' I had to chuckle as his delivery. His passing comment confirmed to me that at this moment in time this person was one of my favourite people on the planet…*"One last thing..." he said. "Don't go into space in the next few years...No gravity...Bad for bones!"*

I came out of that appointment so happy! To hear that I was not degenerating was an amazing thing. All I could picture before that meeting was myself crumbling away but I wasn't! Well not yet anyway. Having experienced such lows after my last appointment and resisting the urge to contact those who bullied me and tell them exactly what I thought of them, I now felt really happy. The hospital was near the Kings Road so Mum and I shared our joy with the shops and I headed home feeling so much happier than I had felt in ages. A man who knew what he was talking about had reassured me with his knowledge. That's all I had ever wanted.

Progressing from Seeking to Living

With my diagnosis and causative factors now confirmed, I progressed from a diagnostic journey to one that involved now living with my condition. I found myself in the position of now having to accommodate my new awareness of my bone health into my life. The journey to a new normal was one punctuated by bouts of fear and uncertainty. Accommodating others into this new world of knowing was something that I was never truly comfortable with. When I did tell people about my condition I could see the shock in their faces and their sympathy would hit me like a bolt of reality. On telling one colleague his reply of 'So what is the prognosis for your disease?' highlighted just how little it would take in these early months for me to start to panic once more about the potential reality of my future. I had a label, a condition. I had a bad thing which I kept trying to forget about and then when I remembered, it knocked the wind out of me. The common theme was that I always ended up trying to put other people at ease with my news, rather than sit there and admit that yes, it was an horrific situation, and at the moment I was feeling like it would define every aspect of my future. I actually, just for once in my life, wanted to be average and normal and have an uneventful happy life with marriage, babies, giggles and cuddles but nope…..I was dealing wth this situation instead! The roller

coaster of emotions was exhausting yet still I tried to protect others from the true depth of my despair.

My relationship wth Citalopram continued to be a difficult one. It was so hard for me to reconcile that I was on a medication that I knew could potentially be causing me harm. The struggle was that I felt I would rather be on that medication than have to deal with how I would feel if I wasn't on it. The doctor was very reassuring. He said I was on such a small dose that if that made me feel normal to just stop worrying about it and take it. He said adrenaline and anxiety would do far more harm to my body in the long run than the effect of citalopram on my bones. I think I just needed someone to reassure me that it was okay to admit that I needed help – despite my previous mistrust of the medical profession I found comfort in this GP as he acknowleged I was having a tough time and help me reconcile my internal struggle.

To give myself something to look forward to I had a snowboarding holiday with friends booked for January 2012 and I realised that I would need to inform my travel insurance company of my new condition. Despite me now knowing that I should never have been given the label of 'osteoporosis', it was on my GP notes and so if I didn't declare it and something happened, there would be the potential for the insurance company not to pay out. I was seriously wondering whether to actually tell them or not. What would I do if they wouldn't insure me for winter sports? If they didn't insure me would I still go? If something did go wrong and I broke something I would have had to pay and that could get rather expensive. My colleague and I were talking about this one-day and I started to cry. I just didn't what to have to think about this. I was angry once more. Could I really live with this level of emotional baggage for the next however many years? I was scared that it was actually going to send me mad. I needed a break from worrying about it, but I only worried about it when I had to think about it. If I thought about it I got upset. If I got upset then my anxiety went up. I was CONSTANTLY (it felt) trying to keep my anxiety under control at the best of times and it was exhausting. I literally felt at this point (September 2011) like I was on the edge of a breakdown. I needed everything

to stop. I needed some time away but it was only the 1st week of term! With weeks to go before the snow holiday I still hadn't called the insurance company and finally plucked up the courage at the start of December 2011. I rang up to say I needed to update my details: 'I have osteoporosis' 'Right let me pull up the osteoporosis questions. Right, how many fractures have you had in the last 5 years?' 'Two.' 'Does your GP know of your diagnosis?' 'Yes.' 'Right that's £27.50 to pay then to cover you for osteoporosis.'

Oh, well that wasn't as traumatic as I anticipated! I didn't particularly like having a set of present questions assigned to be and checked several times that should I break anything I would be covered and yes all was fine. I'm not sure how I felt about having a set of questions assigned to me through!

My emotions started to calm a little after my last meeting with the osteoporosis consultant in London, but were still very volatile in the months following my diagnostic journey. I sometimes felt as if I was living with a black cloud over my future and I didn't want to acknowledge it, give it the time of day, or think about it anymore than I had to. I was still so angry I had got weak bones. I was angry that I couldn't just be normal and not continually be fighting anxiety and now these bone issues. I could, on the one hand, go for weeks without getting upset but if I ever felt unwell or stressed, everything was heightened. Bad weather drew my awareness back to my physical vulnerability. Every time I walked into a building, from a wet outside, I was paranoid of falling. On a wet and rainy January morning (January 2012 – eight months post diagnosis) I had to go into town and as I walked into the shopping centre my foot slipped. I held myself and didn't fall but immediately burst into tears. I couldn't walk for fear of slipping. I felt so vulnerable. Scared. I wanted to just sit on the floor and someone come and hug me and get me to safety.

I continued to try and engage with my gym training programme but my adherence was hugely affected by how I was personally feeling about my condition. What used to be an activity that felt like an escape from the stresses of the world was now just a reminder about my bones. This reminder was due to the lump of my rib fracture site

showing through my gym clothes and I was now training with a specific goal of increasing bone density rather than just training for enjoyment. A previous coping mechanism was now a stressor in its own right. If I didn't have that visible lump I felt I was getting to the stage now (nine months post diagnosis) where at times I would forget about my bones for complete periods of time rather than have it as the lens through which I observed everything else.

The pattern of not thinking about my bones, being reminded, hurting and then not thinking again continued until my condition became visible once more 11 months post diagnosis. I managed to get the door leaving A & E before starting to cry. I had been fighting tears since they sat me on the bed and said "The doctor and I think you have a fracture, so we need to back-slab you, re-x-ray in 1 week and then put you in fibreglass for 6 weeks." The nurse then left me on my own while she went to get the plaster trolley. My invisible condition had become visible once more. I don't think that nurse, despite knowing I had low bone density, realised the enormity of the news she had just given me.

I had been jogging around the block three mornings a week for the previous two to three weeks to a get some outdoor exercise and be get bikini fit. I didn't run on this particular day but as the day went on my foot started to hurt more and more. By the time I finished my meeting with Nick, who had started my diagnostic journey to osteoporosis, I found it hard to walk and drive. By the time I got back to University, weight-bearing was getting intolerable and my drive home involved nauseating pain for each gear change. I had to pull over. I wasn't safe to drive. I called my boyfriend Pete, who was at home, said I had done something to my foot and please could he come and collect me as I was only two minutes from home. He announced that he was going training so if I was worried I should take myself to A&E.

I slowly continued my drive home desperately avoiding changing gears and by the time I tried to get out the car, my foot left like it was both cramping and on fire at the same time. My landlady lived downstairs from us and had previously worked as an Accident and Emergency nurse. She saw me struggling to walk and came out. My

foot was red, hot and I was no longer able to weight bear. She offered to take me to hospital but, not wanting to cause I fuss, I said I would go upstairs and ice it for a bit and see if it calmed down. I got half way up the stairs by hopping but had to stop. Sitting on the staircase I called my sister for help and she and her husband arrived 10 minutes later and took me to Accident and Emergency.

I checked in with the receptionist. "I think I have fractured my foot." "How did you do it?" "I think it was through running…I have osteoporosis and I think it might be a stress fracture." "Osteoporosis? At your age? How did you get that then?" It was a reaction and series of questions that I was getting more and more accustomed to so I responded with my standard reply "Underweight and bullied as a child - Never quite made enough of a skeleton when I had the chance." "Oh!"

After an hour wait for triage, an announcement was made that the waiting time was now 4 hours and any non-urgent cases should go home. I hopped to the reception desk, and said I was going to go home. After all, if my foot was broken it would still be broken tomorrow, so 24 hours would make no difference. "No love, you aren't going anywhere!"

The triage nurse said I needed an x-ray. I waited for a few more hours and hopped to reception once more. I was tired, in pain and just wanted to go home. The receptionist and nurse who happened to be walking passed, were so lovely and within 10 minutes I was in x-ray. The radiographer made small talk. "How did you do this then?" "I've been jogging for the last few weeks and I think I've damaged it somehow doing that." "You've got osteoporosis, haven't you?" "Yes." "Well you shouldn't be jogging then should you?!"

My best friend Dave was due down that evening to do some work at the University with me, so I called him, explained what had happened and asked if he could come and get me when he arrived as I had had enough. A few minutes later a smiling nurse started walking towards me so I stood up and started to hop over to meet her. I honestly thought that she was going to pull me to one side and say it was fine and

send me on my way. But she kept walking. She walked passed reception and towards the cubicles. “We think it's fractured...” The fourth metatarsal was showing an area of potential fracture but it was hard to tell and with my history they thought it better to be safe than sorry, so I was to get my lower leg and foot plastered. The nurse went to get me scrub bottoms to change into so she could apply the cast and I started to implode. This couldn't be happening. I couldn't have fractured again. That would have been three fractures in 18 months.

I text my sister and Dave to say I was getting put in plaster and then would be done. The nurse returned and said it was hard to tell but the doctor did think there was a fracture there. She added that perhaps I should go on some medication for my osteoporosis. In my head I screamed “I CAN'T GO ON MEDICATION. I HAVEN'T HAD CHILDREN YET. IT CROSSES THE PLACENTA. WE DON’T KNOW THE LONG-TERM EFFECTS. WHY DO I KNOW MORE ABOUT THIS THAN THE PROFESSION I AM RELIANT ON FOR HELP?” Instead I smiled at her and said nothing.

As I made my way out of cubicles on my newly acquired crutches, I saw Dave sitting in reception. He looked up. He saw my pain. He briefly dropped his head into his hands before standing up to come and take my bag and help me out the door. At the door way I couldn’t hold it together anymore and leant against the wall and wept. I was so overwhelmed with sorrow. All I could think about was how there was absolutely no point in living if all if all I was going to do was break. I just couldn't see a happy future if I was now going to fracture so frequently. I genuinely didn’t want to be here. I didn’t want to live this life. It was just too hard.

Dave was amazing. He hugged me. He reassured me that everything would be ok. He told me off for running on concrete with old trainers and said that was enough to cause anyone to hurt their foot like I had. He dropped me home and I felt hopeless. I called my parents and Mum answered. I said what I had done, complained about how Pete had left me to deal with it all on my own and for the first time ever in front of my parents I stopped trying to be brave and I cried. I still said I was sure I was just tired and hungry and I'd feel better after a good night's sleep but I think they saw

through it. Everything seemed to be going so well. I was training well, looking better, I was generally happier and now I was back to square one. I finished pouring my heart out to Mum, set up the sofa bed and had a rubbish night's sleep with my leg elevated on a pillow.

Dave picked me up for work the next day. Everyone I met asked what I had done..."I've got f'ing tennis elbow, what does it look like I've done?" My Sports Injuries and Rehabilitation students gave me a round of applause when I got to the lecture theatre for their session. I got through the day due to sunshine, painkillers and the smiles from the students but after a day on crutches, with my back, shoulders, arms and wrists now aching, by the evening I was feeling low again. I called Mum and Dad again for a chat and having spoken with Mum about my day she said Dad wanted a word. The line started to crackle and she said "Oh hang on, you're cracking up!" As my Dad took the phone he said "Quite literately!" and with that one comment the atmosphere lifted and we all had a good giggle. Dad told me how he and Mum had been quite teary the night before. I had never heard him talk like this before. I was only aware of him crying twice in my lifetime; when our family dog was put down and when my Granny passed away. To hear my situation had made him feel tearful was really sobering. He said he felt so sorry for me and was sad that things were going so well and I'd hit this setback. He was sad I wasn't getting the support I needed from my boyfriend. Even as I write this I get teary as I wish I could have just sat down with Mum and Dad and said what things really were like at home and how hopeless my life felt at this time. I was living with an abusive man but didn't know how to get out. I was stuck in a life with no hope and I couldn't see a way forward. This just wasn't how things were supposed to be. But I couldn't add to their pain. I didn't want them to feel any worse than they did already.

Back at work and again the reactions of others both fascinated me and made me sad once more. A colleague at work saw me on my crutches and said "Oh lord – What have you done?" I told him and he asked if it was "exacerbated by my other issue." It was like the Scottish play – Never let it be mentioned by name. I said it was probably caused by that and he put his hand on my shoulder and said he was "so

sorry." The lump in my throat and prickly eyes returned. I wanted to lose it and shout and cry about how completely terrified I was and how I actually didn't see the point in living if it meant fracturing to the point where I was living with a disability – I didn't want to be a little old lady with spinal fractures and a stoop.

One of our friends had a nice chat with me though at her birthday party. She sat me down and said I was just going through a period of adjustment, a phase of working out my limitations and that there was loads I still could do…It was just there were some things I couldn't. She went through the same adjustment process when she was diagnosed with diabetes a few years ago. Those words provided such comfort. Instead of just telling me it would all be ok, there was an acknowledgement that it would have an impact on my life but that it might not be as impactful as I feared and I just needed to get used to the idea. I wanted to be able to curl up for a few days while I 'adjusted'. I just wanted to be looked after.

After 5 days my foot no longer hurt like it had and I anticipated that when they re-x-rayed me in a week they would see the fracture was not as bad as feared and I won't have to be in plaster anymore. I wondered if, having fractured again, maybe I should have another DEXA scan sooner rather than later. Whilst I hated it when my condition became visible through fracture, I also hated the invisibility and uncertainty of bone density itself.

My experience of life on crutches was starting to get me down. My hopping foot was so sore. I couldn't fit myself, my crutches and my backpack in the car front seat without being utterly uncomfortable. My sister was kindly driving me around but her car was such a mess I couldn't put my foot on the floor - I just couldn't do anything with my stupid heavy cast. My hands, shoulders and back ached constantly. I couldn't just get in or out of the car, I couldn't pop upstairs – But ultimately, I knew why I was feeling so frustrated and fed up. The fracture clinic called first thing one morning to say that they needed to move my appointment to the next week so I was facing another seven days in this uncomfortable cast, with these stupid crutches and I just couldn't face it. I begged them to get me an appointment sooner and luckily,

they called later in the day to say a new clinic was being held in three days. If I could attend then there was an appointment free. I was so rubbish when in no-mans's land. I needed to see an x-ray so that I could see if there was a fracture there or not. I couldn't deal with not knowing what was going on with my body. I had been getting so frustrated with everything aching. It made me feel so vulnerable. I had been so aware of every impact and roll of my hopping foot. I went to buy myself some cushioned insoles because I couldn't bear the thought of excessive force going through my bones and stress fracturing something else.

I found talking with a colleague reassuring at this time. She was saying that after she ruptured her anterior cruciate ligament she went through a period of being really aware of her knee and feeling quite vulnerable. I explained that I felt like that about my whole body. When I was using the crutches I thought at least I was loading my upper limbs but then when my wrists ached I wonder if I can get stress fractures there from the crutches? I was just so fed up with not being able to use my body. I hated not knowing what state my body was in. I was so worried that if I would just see a Registrar in fracture clinic, and they would be the one to say either stay in plaster or that I was okay. I didn't trust them not to get it wrong. I hated not trusting the medical profession but I just didn't. With my scaphoid I was told six weeks and it was 11 months. What would happen if a shoulder specialist was covering fracture clinic and just guessed at what to do? I was tempted to just get a copy of my x-ray and send it to a foot consultant I once did some work with. I trusted him. I was so terrified about not having the best outcome as I knew my foot could become arthritic and affect my legs and back in years to come if it wasn't treated properly at this point. I was so scared. I literally had no faith in the medical profession and I hated not knowing who to trust.

The day before my fracture clinic appointment and I was trying to concentrate on marking and failing miserably. I was reassured in that my foot was no longer painful. I couldn't imagine a need to keep me in plaster for another six weeks but I had also come to realise that I felt safe in plaster. Just the same as when my wrist was in

plaster for all that time, it became comforting, reassuring and I felt all together less vulnerable when in a cast.

Fracture Clinic - April 4, 2012 – 1 Year post diagnosis

Fracture Clinic day was an intense day. When I arrived I saw that the consultant who had operated on my wrist was leading the clinic. I felt pure relief. I trusted this man. He was a no nonsense *get on and fix it* man. I also however, saw the registrar who had tried to take my wrist out of plaster after about eight weeks only for me to have to return the next day when someone senior had reviewed my x-ray and got me straight back in to be immobilised once more. There was no way I could let that man make the call on my foot. I just didn't trust his judgment. I went to the receptionist and asked if it was possible to see the main consultant himself. It meant a longer wait but I was happy to wait as long as it meant I could see the consultant I knew. I went for an x-ray and the radiography asked how I did my foot. I said I had been running. "Is that wise with osteoporosis?" I couldn't go through explaining anymore. I smiled and said "I guess not!"

After a few hours I saw the consultant and he reported on my x-ray. There was an area under my fourth metatarsal that still looked suspect. I told him about my osteoporosis and he said he would be happier for me to be in a position to be able to keep weight bearing rather than keep me immobilized. I was out of plaster but back in for a follow-up x-ray in one month to check healing. He asked if I was on anything for my osteoporosis. I explained how the consultant in London had said not to take bisphosphonates as I hadn't had children and not enough was known about the side effects. But the question just made me frustrated once more at the lack of dissemination of research findings in literature, into every day clinical practice. I left this appointment out of plaster, with a follow up booked for one month's time and a new resolve to keep away from the medical profession.

Helping Others Yet Hurting Myself

During the months of my diagnostic journey I had joined the National Osteoporosis Society (NOS). I felt it would be a useful means of keeping up to date with the

osteoporosis research landscape and make contacts. As part of the membership I received a quarterly magazine. I read the medical elements and avoided the patient stories. Now 11 months post diagnosis they still made me want to cry but the magazine came in a bag with several other leaflets that I had absolutely astounded me. There was a leaflet for insurance for the over 50s, which I guess made sense as the typical age of a person with osteoporosis would be above that. But, there was also a healthy living brochure full of hearing aids, portable adjustable sofa tables, and instant portable bidets! If this wasn't bad enough the full size adult bib and bladder control underwear were just a step too far. Looking back at the patient liaison event I had been to earlier in the year I could say at least 70% of those attending had no use for anything in that magazine. Even those in their 50s, 60s and 70s, who I met at that event would be insulted by the assumptions made about them just because they have been identified as having osteoporosis.

One year post diagnosis I notified the NOS about my PhD research and personal journey and they seemed interested in my being involved in raising awareness of the importance of bone health in adolescence. I was asked to be an ambassador for a number of awareness events. The first of these events was just over a year post diagnosis. I was invited to be an ambassador for an event to promote cricket in schools as a means of getting children to be physically active and have controlled exposure to sunshine - both a means of improving their bone health. I was excited. I felt empowered. I was looking forward to showing the event attendees that anyone can have low bone density and get them talking about positive change. As the event drew nearer however, I was surprised at my reaction to going public with my condition. I realised I didn't want people to know I had a diagnosis of osteoporosis. I would always try and phrase it in any way I could to avoid saying "I have osteoporosis". Two weeks before the event I received the briefing document outlining who would be there and what my role was.

After reading this briefing I felt like I was going to be the circus freak everyone would want to prod and poke, and I started to cry. I hadn't cried about my bones since March when I broke my foot. But reality hit me when I read that document and there

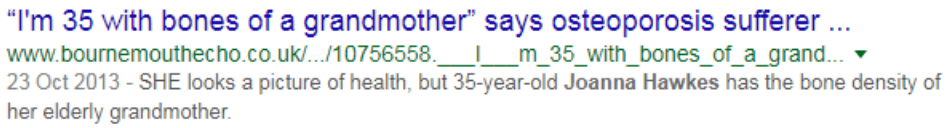
was one particular trigger……I was going to be an ambassador alongside a young man who had spinal fracture. I realised I was terrified of spinal fractures. And not just "gosh they would be tough to deal with"…I literally could not cope with the idea of sustaining compression fractures to my spine. Any other fracture site and I knew deep down I could deal with it but, for me, the spine was the ultimate incapacitation and vulnerability. Other fracture sites I could get plaster for, look at and see. The spine was my very core. If my spine fractured then that was it…the condition had got me and penetrated my very being. It literally terrified me. I cried proper fat tears. I did the event. I hated it. The NOS spokesperson announced that I was there "if anyone wants to know what it's like to live with this crippling condition?" and I cried all the way home. The event that evening…the reality that I was osteoporotic …the stories I heard and people I met…..my future terrified me once more. I had managed not to think about it for months and I was sure the next day I would get back to being proactive but for next week I struggled more than ever with pure panic.

In the October of 2012 year (18 months post diagnosis) I was once more invited to join the NOS and be part of the International Unbreakable Embrace campaign. This involved going to Clarence House to meet the NOS patron HRH Duchess of Cornwall. I was less emotional about this event, despite meeting others with the condition. I felt I was being proactive, that my involvement meant that my experience of osteoporosis would not be in vain if I could somehow raise awareness.


Her Royal Highness The Duchess of Cornwall takes part in the ...
https://www.iofbonehealth.org/her-royal-highness-duchess-cornwall-takes-part-'unbre...
20 Oct 2012 - Her Royal Highness The Duchess of Cornwall is pictured here, at Clarence House, London, with people who have suffered fractures due to **osteoporosis** or brittle bone disease: Hugh Macpherson (3 fractures: spine and ribs), **Joanna Hawkes** (2 fractures: ribs), Beverley Collins (1 fracture: leg) and Shona ...

[PDF] Working together for a breakfreefuture - The National Osteoporosis ...
https://nos.org.uk/media/2016/annual-report-2012-sh.pdf
Shona Mills and **Joanna Hawkes**, all of whom are affected by fragility fractures. Our "Unbreakable Embrace" photo appeared on websites throughout the world. Working together for a breakfreefuture. Understanding. The UK Allied Health Professional Network provides support to those working in the field of **osteoporosis** and ...

In the following months more press opportunities came my way due to my research but I started to notice a trend in the words used with each of the published photographs, or the introduction I would get at events.


"I'm 35 with bones of a grandmother" says osteoporosis sufferer ...
www.bournemouthecho.co.uk/.../10756558.___I___m_35_with_bones_of_a_grand...
23 Oct 2013 - SHE looks a picture of health, but 35-year-old **Joanna Hawkes** has the bone density of her elderly grandmother.

"If anyone would like to understanding what it is like to suffer with osteoporosis then please do talk to Joanna." "Joanna Hawkes – Living with the crippling condition of osteoporosis." Emotive words were always used, and yes I could relate to each of those headlines, but I felt iit was up to me to label myself depending on how I felt, not anyone else. I was not *suffering*. Suffering implied hopelessness, depression, vulnerability, dependence and that was not me. In fact was not most of the other people with osteoporosis I had met. I hated the use of inflammatory words just to make an impact.

The final straw, in my decision to stop working to publically raise the awareness of premenopausal osteoporosis, was when my university released my medical status to the county without my permission. I was greeted at work one day by a colleague saying it was a good article I had done in the county magazine. This would have been a lovely complement if I had indeed completed an interview for this magazine but I had no idea what he was walking about. I was frantically trying to search the internet for a copy of the article. What had been said about me? I was so angry. If the article was just talking about my research then that was actually okay with me. If they had told the whole of the county that I had osteoporosis, well, that was something that I was not okay with. No one had the right to talk about my health without seeking my permission first surely? It was me, my body. For me at this time it was okay if I decided to tell people but no one had the right to tell people unless they had my permission. I was always so careful how I phrased my situation. I talked about my *experience* in research etc but I never once said that I had osteoporosis when writing about my research at this time. My blog was anonymous. The external

university webpage didn't list it. It was up to me who read about me. I was so angry I just wanted to read the article and know what they said. How did they even get the story? How could they not even ask me if it was okay to run a story about me?

I found a copy of the article online and my university had indeed told the magazine about my research but they had also told the magazine about my diagnosis as the words that I had personally experienced osteoporosis were in print across households all over the county.

Do not sensationalize me to make a good story. Do not take that one piece of control I have, away from me. I couldn't believe that no one thought that perhaps ethically my institution shouldn't publicise my medical status without asking me first? Oh my goodness I was so angry. My disclosure of my research had to be on my terms. It's all I had. I couldn't control anything else. I was not ready to just casually talk about my condition to the whole world.

My Second DEXA Scan - July 2, 2012 - 15 months post diagnosis

July 2nd 2012 was an amazing day! I was so happy I could have wept! I had my 2nd DEXA scan and I had GROWN BONE!!! I had, through going to the gym and lifting heavy weights, improved my right hip score so much that I was no longer osteoporotic there! My biggest fear ever with all of this was that I would shrink, break vertebrae and degenerate but today I got the news that I had grown 1cm and my spinal scores hadn't changed at all! I now had a personal goal of another 18 months before the next scan to get rid of this thing completely! I had increased my bone density in the last year despite living in the most horrifically stressful situation so who knew what I could achieve now (two months ago Pete had left me for someone else and I had was finally free to start living again). I felt AMAZING! I wanted to tell the world! The relief was overwhelming. My mum and dad were SO pleased and I was almost feeling embarrassed that I had been going through such turmoil in the last year worrying about it because I had such a renewed hope that I might be ok!!!

The periods of not thinking about my bone health were getting longer and longer. I still had a fear of an unknown trajectory for my future, but as the distance in time from my last fracture continued to grow, so my mind and fears began to calm. Now single my main fear was one of disclosure to any future partners. I feared I was less of a woman as I came with the baggage of a having a condition that might make me a burden later in life. My periods of diary writing and blog entries were far less frequent following my second dexa scan, I was happy. I no longer felt the compulsion to write. In the December of 2012 I met my now husband. As part of our getting to know each other I told him I was completing my PhD and if he wanted to read about the topic he could read my blog. He read it. I called me straight away. He said it changed nothing and I just had to promise not to break anything or hurt myself while we were together but he would look after me if I did!
This time signalled a natural end to data collection for this study.

[March 2018 - 6 years post diagnosis

By way of completing the story I wanted to provide a very brief overview of my current position. Tony and I married in May 2014. Ten months after our wedding, I gave birth to our daughter. One year after our daughter's birth I requested another DEXA scan. I knew pregnancy and breastfeeding could have an impact on bone density and once again wanted to know where I was, in terms of my bone health. The result was that my bone density was now worse at each site, with T-scores lower than they had ever been. At this point I decided that I would not have any further DEXA scans. The results only served to cause me emotional upset and offered no further knowledge on how my future might look. I have only had one small fracture to a toe since my foot stress fracture. The rib lump still upsets me.]

4c. Part Two: Reflections on Experience

This section of Chapter Four explores my experience of living with premenopausal osteoporosis as a "life told" (Bruner 1984, p.7) in order to continue to answer the research question of How have I, a young active female, experienced living with premenopausal osteoporosis? As discussed in Chapter Three, the methodology utilised within this PhD research was influenced by Johnstone's (1999) method of reflective topic autobiography. This section presents the "emergent themes, distinctive qualities of the experience, meaning, [and] understandings" (Johnstone 1999, p.7) and includes exerts from both my diary and blog writings, through diagnosis, up until 2 years post diagnosis. These reflective accounts have been produced as a result of the Incubation, Illumination and Contemplations phases of the Reflective Topical Autobiographical method (Johnstone 1999), from the story that was my life as experienced. Seven reflective themes are presented in the following sections:

Engagement with the Medical Profession
Information Seeking and the Educated Patient
A Stranger in a Biomedical Land
Managing Visibility and Disclosure
Social Interactions
Impact on a Physically Activity Lifestyle
The Emotional Journey

Reflection One: Engagement with the medical profession

Throughout both my diagnostic journey, and in the years following my diagnosis, I had cause to engage with a number of professions within the health care service. These professionals have ranged from; Physiotherapists (involved in the management of my initial wrist fracture); Chiropractors (who were involved my initial scanning); General Practitioners (GPs - for test results, initial conversations about causes and treatment); Radiographers (for DEXA scans and x-rays) to Consultant Orthopaedic Surgeons; Registrars (when I sustained a third fragility

fracture 11-month post diagnosis); Consultant endocrinologist; and Consultant of Osteoporosis (whom I sought out privately). As I reflected on my journey through my engagement with these professionals I was very aware that my experience had been one punctuated with inconsistent 'polar' experiences. At one pole had been the kind and reassuring words of my friend Nick, the practitioner who first mentioned the term 'osteoporosis' to me, and I would also include the two Consultants in Endocrinology at this end of the continuum. Each of these practitioners treated me with kindness, going above and beyond what I would expect their role to be as demonstrated by their quiet listening and considered delivery of news. Appointments were never rushed and each practitioner followed up our encounters with either a summary letter or phone call to me. At the other end of this spectrum however, was the practitioner who delivered my heel scan results, those who I encountered in emergency medicine (when I needed follow up scans and x-rays) and oscillating in the middle of the spectrum were my experiences with various General Practitioners. These encounters were variable depending on which GP I saw within the practice.

The two characteristics that defined these poles were my level of trust in the knowledge that the professional had in the sphere of my condition and their ability to talk to me as a person not a patient. I interpreted the latter as their acknowledgment that this was a situation that would cause me shock and upset and that I was a young woman undergoing testing and investigation for a condition that I had never expected would enter my world. With consistencies of experience being broadly comparable by profession I reflect on these encounters in the following three sections.

Experiences at the Chiropractic College

To have a clinician as a friend, whom I could call on when I injured my ribs, was both a blessing and a curse. Because we were friends I knew that he (Nick) could help me in treating my injured rib. But by having those connections I started a process that I often wish I had never initiated. Had I not worked in the field that I do, and had I not had someone I could text to ask for help, my rib would have remained

uncomfortable for a few weeks and then healed itself. I would have still had a palpable lump but I would not have the diagnosis that I now have. My curiosity in the human body has driven a successful professional career and now forms part of my daily role as an academic. If only I did not have a morbid curiosity to understand the body I would never have had to go through the emotional turmoil that was so pronounced during the time I was engaging with medical professionals. But I did start that journey and Nick supported me both as a clinician and a friend. He was always happy to receive an email from me asking for advice or providing an update and he would respond with his usual dry and slightly off the wall sense of humour. Having this support provided an outlet for a clinical conversation in a friendly environment. Nick was accessible. One email away whenever I needed to offload or mull over a thought process with someone.

My experiences of his colleague were in stark contrast. Still to this day I cannot understand how someone could deliver a diagnosis of osteoporosis in such a detached and aggressive way. Her comments were accusatory, she mentioned 'death' and 'osteoporosis' in the same sentence and in no way alleviated any fears I had following her news. There was no element of empathy from this woman. She spoke to me as if I was a nuisance and displayed no compassion.

Experiences with General Practitioners

I knew as soon as I walked into the GP office that I had osteoporosis. He (the GP) had not yet said anything but I could see the prescription for bisphosphonates, calcium and vitamin D on his desk. Perhaps this GP was still under the illusion that is so often the power dynamic seen in medicine…that he knew more than his patient. I however did know what that prescription meant and so I 'officially' got the confirmation of diagnosis from a piece of paper on a desk before the practitioner had even spoken. His focus in that consultation was on treatment. No mention of finding a cause. His prescription seemed a matter of course as he presented a well-trained response to a diagnostic T score on a computer.

Very quickly in both that appointment and in appointments that followed, it became clear to me that I knew more about my condition and health status than the GPs I was seeing. Whilst the GP wanted me to start bisphosphonate treatment, I was more concerned with finding a cause and so requested blood tests as a starting point to build a picture of my skeletal health. I found myself in the position of educating my GP on their meaning and relevance:

> "So, I had the results of my second blood tests back. It turns out my first blood test highlighted I might be anaemic so they were testing me for that. I called my GP and politely pointed out that as I (and my brother) both have the thalassaemia trait (ie small red blood cells, comes from eastern Europe somewhere!!!) we ALWAYS show up as anaemic but never are! He agreed, said he should have twigged that, apologised for the unnecessary blood test and said I needed to be referred to an Endocrinologist for further investigation into the elevated parathyroid"
>
> (24/05/2011. Blog Post. One month post diagnosis)

It was at this point that I knew the traditional paternalistic model of health was not applicable. I knew I had a deeper level of knowledge about my medical history than the GPs at my practice and I started to feel a lack of trust in them ever being able to help me attribute my condition to a cause. This attribution was an important step for me in processing my diagnosis.

Growing up in the 1980's I was, at the start of my diagnostic journey, still of the opinion that Doctors would have the answer to all medical questions and that they were to be respected and trusted. Yet in this situation, when I had completed the first part of my information seeking following diagnosis, I was feeling very alone. The people I wanted to trust and to tell me what to do, by their own admission, did not know what to do with me. All I wanted at this point was for someone to have an authority on my situation and take control...yet this was not available at the GP level. My position outside of the traditional demographic for my condition was outside of their scope of practice. I knew very early on in the process that I needed to engage with someone with a deeper level of expertise and so sought out private appointments with Consultants in the field. I explore my relationship with these

consultants in the next section of this chapter. One GP experience, in particular, led me to wonder if General Practitioners had a place in my life at all, in relation to this condition.

> "Today is an amazing day! I am so happy I could cry! I had my 2nd DEXA scan today and I have grown 1cm and improved my right hip score so I am now only osteopenic! My biggest fear with all of this was that I would shrink, break vertebrae and degenerate but to get the new today that I have actually increased my right hip density is amazing!"
>
> (02/07/2012. Diary Entry. 1 year 3 months post diagnosis)

On July 2nd 2012, 15 months post diagnosis I had my second DEXA scan and having spoken with my radiographer within the scan itself and told her I was completing my PhD on my experiences of osteoporosis, she spent a great deal of time going through my scan results with me and explained that I had, in fact, increased my hip score by such an extent I was now just inside the osteopenic bracket and so no longer technically osteoporotic. Clearly, this was amazing news, and as before, I would have to book in with my GP to get the paperwork and official result of the test. Unable to get an appointment I requested a call back from the GP for the result and asked for the paperwork to be sent to me:

> 'I am on GP avoidance! When I had my last DEXA scan, the lovely radiographer talked me through my results. I had a significant improvement in BMD in my hip so that it was now only osteopenic not osteoporotic. When my GP called me to update me on my results – not knowing I already knew them – he said I was still osteoporotic – what a bastard. He has no idea how articulating to me I had made some bone would make such a difference to my life – Small improvements mean a massive amount to me, the patient. It signifies hope – a completely different future – normality! How dare he not consider the impact of his words on me and just update me with a blanket response particularly when I had made a significant improvement in one hip – So not I refuse to see him again – arse!!'
>
> (05/10/2012. Diary Entry. 1 year and 6 months post diagnosis)

I had already decided early in the diagnostic process that the GP was not able to offer the level of detailed care that I needed and as such had sought help from

private Consultants. Following this relaying of inaccurate information regarding my T-scores and what they actually meant I made the decision that if I ever needed or wanted to talk to someone about my osteoporosis and future treatment I would go straight private medicine rather than waste my time trying to engage with General Practitioners, as I was too far removed from their level of experience for them to treat me appropriately.

[Whilst outside of the data collection period for this study but related to my osteoporosis, the final straw for me in terms of lack of trust in the GP, was after I had had my daughter. I knew that pregnancy and breastfeeding could deplete bone density and I was saddened that despite knowing my medical history, no one at our family general practice seemed concerned about getting me scanned to quantify the skeletal impact having my daughter could have had. A missed diagnosis of milk allergy in my daughter at six months old led me to write a letter of complaint to the practice, that included my upset at this lack of follow up for my own condition. The result of the DEXA scan appointment that came shortly after this complaint was that my bone density was now lower than it had ever been at all three sites (spine, right and left hip). I was officially 'osteoporotic' once more. The report I received still stated 'No further action necessary' leaving me once more in limbo with a condition but no medical guidance on intervention or prognosis...]

Experiences of Specialist Consultants

As alluded to in the previous section, a feeling of needing answers as to the cause of my condition, combined with the feeling my GP was not in a position to supply me with the depth of knowledge I was seeking (and the speed at which NHS investigations were being carried out), I sought out a referral to a London based Consultant in Endocrinology through my private medical insurance. Without even seeing him I knew I would trust what this Consultant would tell me. I had researched his areas of expertise online, and he had research published within the area of osteoporosis treatment and management in relation to parathyroid function. This initial referral was to further investigate the potential impact of my altered parathyroid hormone result on my skeletal health.

The consultant I chose and ultimately saw, had such a command of knowledge in the area of hormones and osteoporosis and very quickly started to talk to me about the link with cortisol (the stress hormone) and osteoporosis. It was he who presented

me with the potential causes of low body weight, late onset of menses, early menopause or parathyroid tumour, having spent time to engage in a comprehensive discussion with me about my medical history and my recent blood test results. The first consultation I had with this man was the first time anyone had mentioned my medical history in relation to my current presenting condition. As we talked about my citalopram within this medical history discussion, he excused himself and went to ask his head pharmacist to research the link between citalopram and low bone density. Within 15 minutes the pharmacist had fed back that yes there was a link, particularly with hip bone mineral density (my worst area).

Perhaps this exploration into my past and potential causative factors was due to the luxury of time that a private appointment entailed, or a deeper level of knowledge than my GP in the aetiology of skeletal formation, but it had a huge impact on me as a patient needing someone to listen to me and understand the process of questioning that I was going through at this point.

One of my frustrations with engaging with my NHS GP was that everything was taking so long. I was told to book appointments weeks in advance, but no appointments were ever available. The next step in getting seen by a Doctor was to try and get an emergency same day appointment yet this always felt as if I was denying someone who had acute illness an appointment and I never felt comfortable with that. Blood test appointments were then another day at another hospital site, and again I had to wait weeks for the results. Having gone privately, I received an appointment within five days, with an expert, had blood tests the same day at the same clinic and received the results by phone within a matter of days, directly from the Consultant himself so I could ask any further questions. This process (in both speed and consistency of discussion with the same practitioner) instilled a sense of calm and trust that meant that I felt I was being looked after and that my experience was being valued. It also helped that this Consultant had a fairly off the wall sense of humour that immediately helped put me at ease:

> "…having done a few placements in theatres with orthopaedic Consultants my general view is, the more off the wall and generally certifiable the Consultant…the better they are!"
>
> (24/05/2011. Blog Post. One-month post diagnosis)

Having been able to rule out both a parathyroid tumour and early onset menopause, my first Consultant referred me to a specialist in osteoporosis at a nearby hospital. Again the appointment was within a matter of weeks.

> "So I have been referred to a top OP consultant at the […] who will investigate me further. My referral letter from the […] doctor said 'I would very much appreciate it if you would see this delightful young woman, she really does need your advice and is quite sensible.' (!!!)…My mother's reply….'Well he clearly doesn't know you very well does he!' Thanks mum!"
>
> (12/06/2011. Blog Post. Two months post diagnosis)

The tone of this referral letter was somehow reassuring. The phrasing felt to me both kind and acknowledging of my unique position for this condition. Both this consultant and the one I was to see as a result of this referral were certainly in their 60s and were both very well spoken. For me this somehow provided reassurance. I felt immediately 'at home' in their company. I felt I could speak with them on an intellectual level without them feeling challenged or belittled. It was a partnership exploring causes, discussing ideas and once they knew I was a PhD candidate, I felt there was a respectful level of expectation and knowing between us. I understood their medical terminology. We could speak at the same level.

> "Last week I went to London with Mum and saw a 'super' specialist on Osteoporosis who was one of the loveliest people I have ever met, and he was clearly the man to chat to about bones. He thinks one of reasons I might have low bone density (combined with other risk factors such as low weight and poor absorption during my teens potentially) is the fact I have thalassaemia trait (funny shaped haemoglobin in my blood cells)."
>
> (12/07/2011. Blog Entry. Three months post diagnosis)

Despite this second Consultant adding another potential causative factor from my medical history (my beta-thalassaemia trait) he also reaffirmed the previous

hypotheses that my low body weight, anxiety, and citalopram use, were all a triad of risk factors resulting in my only having made 70% of the skeletal bone mass that I should have in my adolescent years. The fact he had a working knowledge of thalassemia, knew I was not a traditional patient for that condition and had read up on (and further explored with me) my medical history, all continued to fuel my confidence that I had found the right person to guide me through this biomedical journey.

> "This doctor said unless you are in your 80's and living in a nursing home there is no need to take calcium and vitamin D and that no one under the age of 70 should really take the bone medications which my GP tried to get me on, as we simply dont know enough about them in terms of long term damage and side effects. I came out of the appointment so happy! I just have to continue eating well, going to the gym and 'crack' on with life (excuse the pun!)"
>
> (12/07/2011. Blog Entry. Three months post diagnosis)

I left that appointment above on cloud nine. I was so relieved. The Consultant had reaffirmed all of my concerns about the need for medication. By using humour in his parting words, by telling me not to go into space as "zero gravity was not good for bone density", he ensured that the situation for me was minimised to such a level that for the first time in the weeks since the diagnostic process began, I felt as if I could cope. He also, however, quite unknowingly reinforced my lack of trust in my GP, who I knew would have prescribed drugs, not indicated for my population, as a reaction to seeing my T-score. That GP could have damaged the growth of my future child.

Experiences of Hospital Practitioners

The theme of lack of trust in the medical profession had developed quite strongly over this time and on reflection I know it was my previous experience of the management of my wrist fracture that had started that mistrust one year before my osteoporosis diagnosis. Within that experience (as described in Chapter Four: Part One) I had wrongly been told by a physiotherapist, who saw my initial x-ray, that my fracture would heal in six weeks. In total, I was in plaster for nine months and had to

have an arthroscope operation before my wrist was healed. After six months in plaster, I wrote a formal letter of complaint to the NHS trust about the handling of my diagnosis. The result of the complaint was acknowledgement that I had indeed been advised poorly and that the Trust would use my case as a development exercise for those working in fracture care. A secondary result was that I was referred to see a Consultant wrist specialist who advised the operation that would eventually lead to the healing of my wrist, eleven months post fracture.

Eleven months after my diagnosis of osteoporosis I sustained a stress fracture to the forth metatarsal of my left foot, having been jogging for a few weeks.

> "I managed to get the door leaving A & E before starting to cry. I had been fighting tears since they sat me on the bed and said "The doctor and I think you have a fracture, so we need to back-slab you, re-x-ray in 1 week and then put you in fibre-glass for 6 weeks." The nurse then left me on my own while she went to get the plaster trolley. My invisible condition had become visible once more. I don't think that nurse, despite knowing I had low bone density, realized the enormity of the news she had just given me."
>
> (31/03/2012. Diary Entry. 11 months post diagnosis. Fractured 4th metatarsal after jogging)

This fracture led to an x-ray in Accident and Emergency, a plaster cast and once again I was back in the 'fracture' system. The experience of my wrist, however, enhanced my fear and lack of trust when I fractured my foot:

> "Fracture clinic this morning. I walked in and saw that the clinic was being run by the lovely surgeon who operated on my scaphoid fracture 18 months ago. I also saw the guy who took me out of plaster too soon for my wrist. There's no way he was making a call on my foot. I don't trust his judgement."
>
> (04/04/2012. Diary entry. 1 year post diagnosis)

Mistrust combined with my own training in injury management. I was frustrated that I was not the person to be able to see my x-ray and decide on a course of action:

> "I need to see my X-ray, so I can work out what has actually gone on in my poor foot! Then I can work out my next 6 weeks!"
>
> (02/04/2012. Blog post. 1 year post diagnosis)

The theme of mistrust was reinforced each time I needed to be involved with anyone within the NHS hospital system due to what I felt was a complete lack of knowledge on researched care and practice associated with premenopausal osteoporosis. Multiple practitioners including nurses, radiographers and (most upsettingly for me) a consultant orthopedic surgeon all demonstrated, by the advice they were giving me, that they had no knowledge of the researched medical guidance on pharmaceutical prescription for premenopausal females, physical activity guidelines and how to manage a non-traditional patient for a condition.

> "The nurse came back and said she didn't think it was a fracture when she first saw me and that maybe I should see my doctor and go on some medication for my OS."
>
> (31/03/2012. Diary Entry. 11 months post diagnosis)

> "The Consultant asked if I was on anything for my OS. I explained how the Consultant from the […] had said no as I hadn't had children and they didn't know the side effects. It makes me so angry – why don't doctors know anything?"
>
> (04/04/2012. Diary Entry. 1 year post diagnosis)

Through the passing of time I was able to recognise that for me, at that time, osteoporosis was my whole world. Through the benefit of hindsight and reflection, I accept that I was perhaps unreasonable to have expected practitioners, who know so much about so many things, to be as up to date as I was on such a niche area of biomedical care. I just so desperately wanted someone to take care of me. For me, the operationalisation of that need was to be exposed to healthcare practitioners with more knowledge than me. I could then relax and focus on my part of improving my condition. I wanted practitioners to recognise me as an individual, with my individual characteristics of my condition, rather than a diagnostic term that a traditional biomedical approach would absorb. By feeling that I knew more than the medical professionals treating me, I felt very alone.

Reflection Two: Information Seeking as an Educated Patient

On starting my journey to diagnosis, I found myself in what I felt was a fairly unique position. I classified myself as an 'educated patient.' My first degree was in Sports Rehabilitation with Health and Human Biology, I had a Masters degree in Sport Science and Medicine, and I was working as an Academic within a University with access to electronic databases for all the most recent research. Between finishing my Batchelors degree and starting work as an academic, I had ten years of working with elite performance coaches on training dynamic postural stability for efficient, consistent performance outcomes and had developed a wide network of practitioners that I could call on should I need broader input on a client's injury status and progression for example. I had been trained in the physiology of skeletal formation and had a number of textbooks that described the presentation and treatment for osteoporosis yet none had ever mentioned a premenopausal presentation. Working in elite sport, I had come across the condition within female athletes who had disordered eating or who presented with particularly low body weight (usually combined with over training), but in terms of non-athletic populations, I had read nothing.

> "All I can picture is that stupid image of osteoporosis in the manual, of air spaces in bones."
>
> (09/02/2012. Diary entry. Ten months post diagnosis)

I could never have anticipated how desperate my information seeking behaviours would be. All I wanted was information on why I might have osteoporosis and what I was going to do about it. I never, in those early weeks, thought beyond just getting rid of it. I didn't allow myself to consider having this diagnosis for a lifetime and so all information seeking was from the perspective of me being a patient. I was a patient trying to find a cause and a cure for my condition. I wanted a non-pharmaceutical intervention that I knew would work to improve my bone health. I emailed contacts in places such as the Olympic Medical Institute desperate for any information the practitioners there might have that might not be common

knowledge. I spent hours at my desk at work reading risk factor articles trying to piece together why my bone density was so low. I needed a cause to anchor my present to my past, to allow me to then reconcile it and move forward with treating my condition.

> "It makes sense now I have had time to think about it and teach myself a little about the 'condition'."

(03/04/2011. Blog Post. One-week pre-diagnosis)

Within this information seeking, I was on a purely biomedical mission. With a strong background in science, I wanted unemotional hard facts, interventions, statistics and outcome measures to hold on to. I certainly did not want to read any patient stories, as for me that made the diagnosis too real, too long term and too upsetting. If I were to read how the diagnosis might affect my life, it would be to acknowledge that I would still have the condition as I aged and for me, that was not an option. The thought of not 'fixing' my condition would cause my chest to tighten in panic.

> "I only read the medical bits 'cos the patient stories make me panic/want to cry/feel hopeless etc."

(10/03/2012. Diary Entry. 11 months post diagnosis)

My position as an educated patient however made this information-seeking journey an incredibly difficult one. It became apparent that knowledge was not power for me in this situation. Knowledge led to frustration, anger, disappointment and a very strong feeling of isolation as my information seeking persona moved slowly from that of a patient trying to find causes and cures, to that of my practitioner self who was reviewing interventions, from a musculoskeletal physiology perspective. It became obvious to me that there was no research on my population and I struggled to reconcile the design of many of the exercise prescription interventions in terms of exercises chosen and the intensity and weights used. I became despondent wondering why there was such a research gap when for me exercise prescription

would always be a first choice of intervention over pharmaceuticals no matter what age the diagnosis of osteoporosis.

By the time I had started my research into premenopausal osteoporosis from an academic perspective, I had transitioned from a patient seeking advice and help, to a researching practitioner questioning the literature I was reading. I found myself tentatively reading forums to see what questions others with the condition were asking. The breadth of questions being asked on the forums highlighted to me the lack of available information for patients.

> "I also feel really sorry for them though [users of the NOS forum] - There's questions about medication, exercises, types of cheese to eat – NO ONE knows what to do for the best! It's heart-breaking and so frustrating."
>
> (09/02/2012. Diary Entry. Ten months post diagnosis)

My information seeking was a desperate attempt to regain control. It was also a distraction from accepting my diagnosis and the life that the diagnosis might mean for me. I managed to turn everything into a distraction from accepting that this was a *fait accompli* for me and would use any opportunity to divert my attention away from my own fear.

> "Crutches have been thrown on more than one occasion. They are hideous and ridiculously badly designed but I think I have worked out a way to redesign them and fortuitously work have a Sports Medicine technology meeting in 2 weeks so I will be putting forward my redesign at that!!!"
>
> (02/04/2012 – Blog entry – 1year post diagnosis)

My final transition from patient to practitioner/researcher, to pure researcher was complete when I found I was able to read research about patient experience through an objective, rather than an emotional, lens. To be able to read patient accounts without having a physical reaction to the words I was reading allowed the research (this PhD study) to start to accelerate in the direction that it needed to, in order for an analysis of my experience to be of use to others. Having made the commitment

to research my experience in 2012, I was not in the position to work effectively as a researcher on the topic until 2016. Information seeking after this time was for the research, to academically and philosophically underpin the requirement to contribute to the literature and start to lessen the information gap that was evident from my initial explorations as a patient. The process of information seeking for me, from pre-diagnosis in 2011 to 2016, combined with my knowledge as a practitioner and researcher, made those first few years an incredibly difficult and emotionally volatile time. To this day I maintain that I simply knew too much to be able to accept my condition and start the healing process that a diagnosis ultimately triggers. Educated information seeking and processing, led to feelings of frustration, anger, a sense of feeling completely overwhelmed at the task ahead of me in terms of wanting to draw attention to my diagnostic population. Ultimately my information seeking highlighted that I was a stranger to my diagnosis, a non-traditional patient for the condition of osteoporosis, someone for whom there was no obvious researched based health care pathway, someone who was very alone in their journey.

Reflection Three: Managing Invisibility and Disclosure

Issues of Invisibility

Named a silent condition, the only really visible representations of osteoporosis are bone scan results and fracture episodes. The latter may then lead to prolonged pain or disfigurement that would continue to then remind an individual of their condition. For me, two physical manifestations of my condition caused emotional upset; the boney lump from my rib fracture and my third fragility fracture (my first since diagnosis) that was my foot stress fracture from running.

> "What makes it worse is that I am constantly reminded of the fact I am osteoporotic because the rib I broke back in December sticks out in my chest and I can see it through my clothes. Every time I look in the mirror it is there and depending on my mood I will either notice it or not but today that was all it took to turn me from giggling with colleagues 5 minutes beforehand to going next door and having a good cry with a colleague 'cos I don't want to have the label 'osteoporotic'.'
>
> (12/07/2011. Blog Post. Three months post diagnosis)

The visibility for the rib was enhanced to me due to its prominent position on the front of my rib cage and my low body fat.

> "Every gym session is a reminder about my bones because my stupid rib sticks out through my T-shirts and the whole gym seems to be one big mirror with an arrow pointing to it! If I didn't have that reminder I reckon I'm at the stage where I would forget about it!"
>
> (18/08/2011. Diary entry. Four months post diagnosis)

Despite the feeling above, at four months post diagnosis I was having periods of emotional peace with the condition. It was the visible fracture site of the rib that often jolted my into another fearful and emotional episode about what my present low bone density might mean for my future.

> "Dressed smart for work today – my rib fracture showed through my shirt. It's so ugly – I hate it. A constant reminder – Just go away."
>
> (26/01/2012. Diary entry. Nine months post diagnosis)

Invisibility brought with it a difficult dynamic with those that knew of the condition and want to be supportive by asking about progress etc.

> "Andy: "Hey mate – How are you? How are the bones?"
>
> Me: I don't know (I hate it when people say "How are the bones?")
>
> Andy: "Oh right – So is the training working?"
>
> Me: "I don't know! I don't know if it's working until I have another scan – But I can't have a scan too soon 'cos they aren't that accurate."
>
> (28/01/2012. Diary Entry. Nine months post diagnosis)

The lack of immediate objective quantification of my bone density was particularly difficult to reconcile and exacerbated my emotional reaction to the lack of control I felt, when others asked of about my wellbeing.

> "I have one group of peers who I see intermittently but when I do see them it's all 'How are the bones?' Well guess what people – I don't know! And at times I don't care!"
>
> (05/10/2011. Diary Entry. Six months post diagnosis)

For me, to not be able to know for a significant period of time whether my bone density was degenerating, improving or remaining stable was incredibly difficult. It led to extreme questioning and self-doubt as to when to ask for my next scan. The line between the result of that scan boosting my spirits or it breaking me emotionally once more was very fine.

> "I've started thinking quite a lot about my next scan. I know there is a margin of error with them so I don't want to have one too soon and de-motivate myself, but then I do want to know it it's getting work (my BMD that is). It's so scary. What happens if my BMD is worse? Maybe it'll just be the error of the scanner – maybe I'll then regret having a scan too early – maybe I should wait longer?"
>
> (28/01/2012. Diary entry. Nine months post diagnosis)

I have had a total of three DEXA scans to assess my bone density, the T scores for which are in the table below:

T scores (SD)	May 2011 (initial diagnostic scan)	August 2012 (2nd scan – 15 months post diagnosis)	May 2016 (3rd scan – 5 years post diagnosis – 14 months post-partum)
Hips	-2.5	-2.3	-2.4
Spine	-1.7	-1.5	-1.9

Table 7: T scores recorded between May 2011 and May 2016

Having had a third DEXA scan 14 months post-partum (May 2016) and receiving the news that my bone density had decreased significantly, I made the decision to have no further scans. To quantify my bone density only causes me upset and ultimately has no impact on my biomedical treatment premenopause. I made the decision to return to my strength-training programme – the programme that had resulted in an increase in BMD between my first and second scans – once time allows.

Issues of Disclosure

Disclosure came in two forms for me. Disclosing my condition to those who I met, for example, colleagues, a counsellor, etc and then the disclosure of my condition for the purpose of insurance.

For me, the decision of when and how to tell others of my condition was a matter of control. I did not particularly mind people knowing about my condition. I used the process of telling to reinforce to myself a positive representation of all I was going through, in order to minimise the impact on both myself and those I was telling. I often found that I would play down all elements of my experience so that others did not feel any awkwardness in anyway. I have always been one to protect others from feeling negative emotions. I trace this back to my experiences of bullying at school at a time when my parents were going through financial hardship in the 1990s recession. I did not want to add any other stresses to them. I found the range of reactions I received, perplexing.

> "An inability to help seems to also bring out things in other people, that I find quite interesting. Some surprise me by getting quite angry at me saying basically stop acting like you are dying and get on with doing something about it (Pete!). Others feel awkward when you tell them and don't quite know what to say. Others try and be overly positive and I guess I end up trying to put other people at ease with my news rather than sit there and admit that yes it is shit…yes at the moment I am feeling like it will define every aspect of my future and I actually just for once in my life want to be average and normal and have an uneventful happy life with marriage, babies, giggles and cuddles but nope…..I shall deal with this shit instead!!"
>
> (12/07/2011. Blog Post. Three months post diagnosis)

But it was the reactions of others that would often lead me to go through a particularly emotional time. It was their reaction to my news that affirmed that no matter how much I was trying to minimise my experience and pretend everything was fine, I was still incredibly fearful of the impact of low bone density on my ability to have a healthy future.

> "As always it is someone else's reaction which caused me to once again realise the severity of my situation...Telling him (the counsellor) about it and seeing his shock and then sympathy hit me like a bolt of reality. He then said the words which choked me up completely - 'So, what's the prognosis for

> your disease? Oh my goodness I have a label, a condition, I have a bad thing which I keep trying to forget about and then when I remember it knocks the wind out of me."
>
> (03/11/2011. Diary entry. Seven months post diagnosis)

> "Devastating blow' – That's what Nick called my diagnosis and yet again it is someone else's words about my bones that makes me teary."
>
> (13/03/2012. Diary Entry. 11 months post diagnosis)

I did, however, have one incidence where the disclosure of my condition was taken out of my control. Because I was a research active academic in a Higher Education Institution when approached for any interesting institutional research updates, my employer released my PhD topic and story to a county magazine and within the press release had stated I had osteoporosis:

> "Apparently I am in a magazine, but I am fuming – Who on earth thinks they can write about me without my permission? If they are just talking about my research then that's ok – If they have told the whole of fucking Dorset that I have osteoporosis, I will go mental. No one has the right to talk about my health without seeking my permission first, surely? It's ME, my body – it's OK if I decide to tell people but no-one has the right to tell people unless they have my permission…….I am so angry….I have just googled it and yes they say I have 'personally experienced osteoporosis' – Don't take my control away from me. Don't sensationalise me to make a good story…the photo caption says 'suffers with osteoporosis'…This has to be on my terms."
>
> (30/10/2012. Diary Entry. 1 year 6 months post diagnosis)

I refused to let my bone density impact upon my one passion, that of snowboarding. All snow sports are known for their increased risk of fracture or ligamentous injury, but I was adamant that I wanted to continue my winter holiday experiences. The decision whether to tell my insurance company about my diagnosis was incredibly difficult. Despite knowing by this point that I should have been told I had 'low bone density' rather than 'osteoporosis' as I was premenstrual, I also knew that according to my NHS medical records I had 'osteoporosis.' I knew that if anything were to happen whilst snowboarding the insurance company would want to see my medical

notes and so if I had not declared it, they would use it as a reason not to cover any necessary treatment etc.

> "I have to tell my insurance I have OS, or do I? And if I do, will they insure me? and if they don't would I still go? Probably not! So then maybe I shouldn't tell them but if something goes wrong and I have to pay ('cos they ask your doctor don't they) then I would be screwed."
>
> (05/10/2011. Diary entry. Six months post diagnosis)

When I finally made the call to the insurance company the conversation lasted four minutes as I was asked the "osteoporosis questions", charged £21 and was then insured for snow sports! I had not needed to worry, but I also felt somehow confused by the fact that my bone health had been minimised to such an extent that three questions was enough to satisfy an insurance company I was insurable. For me the implications of having low bone density deserved more than just three questions asking when I was diagnosed if my GP knew, and how many fractures had I had in the last three years.

Reflection Four: Social Interactions

Within 'Social Interactions' I reflect on the impact that social support and my interactions with others had on me throughout my osteoporosis journey.

Interactions with Loved Ones

Social support fell into two groups for me: Those who I knew in my immediate family or friendship circle and those who I met as a result of my condition. Those close to me provided a huge amount of support. They will never know how much. I hid how much I was actually struggling, from them.

> "Luckily my best friend had driven 2 hours to be with me at the hospital as soon as he heard I was there and so was on hand to help me get through the evening and since then my sister and her two small children have been my taxi and cheer up medicine!'
>
> (02/02/2012. Blog entry. 18 months post diagnosis)

One person who did not provide any support and who actively used my diagnosis against me, was my boyfriend at the time, Pete. This was a relationship with a strong power dominance element and as such the news of my low bone density was another power play in order to control my emotional state at this time. Luckily finally in May 2012, I was able to escape this relationship, and this was no longer an issue.

> "I missed lunch today (well I just had soup) and Pete's words were 'No wonder you've got osteoporosis!' What a complete bastard thing to say! I let it go and went and cooked but came back and said 'Please don't use osteoporosis to book your point in arguments because I think of it every second of every day and don't need you using it against me – He got shitty and said 'Fine I won't care anymore then!"
>
> (15/02/2012. Diary entry. Ten months post diagnosis)

One positive to come out of this particular side of our relationship, however, was that by my boyfriend showing such complete non-acknowledgment of my condition and emotional struggles around it, it actually helped me to minimise it at the same time.

> "I am actually appreciative of Pete's blatant non conversation and disregard of my angst – It kind of makes it less important!"
>
> (09/02/2012. Diary entry. Ten months post diagnosis)

With this relationship ending, seven months later I met my (now) husband (Tony), and things could not have been more different. To have the true love and support from this man minimized my fears over my future with this condition hugely. The antithesis of my previous relationship, the support I receive is unconditional.

> "I was nervous about slipping over [in the snow] but he [Tony] was always there to catch me – He never let go of me! We were walking downhill and he kept hold of me all the time. In fact he's made me primes that while we are together I won't fall or break myself or hurt myself in any way! He's the exact opposite [of Pete]. I feel completely loved and supported and it makes my bones seem less scary. Before, with Pete, I was <u>SO</u> scared to deteriorate 'cos I know I would have had no support, he would have been angry etc But with Tony I feel so cared for that it means I don't give my bones a second through really." (17/01/2013. Diary Entry. 1 year 9 months post diagnosis)

Prior to meeting my husband I was fearful that no one would want to date a woman with the potential for a fragile future. I was scared about at what point to disclose my condition to anyone that I might be dating. Once I met Tony, these fears evaporated as our conversation naturally moved towards my PhD and my potential of weak bones. My news was met with the requirement to promise never to hurt myself…and that is a rule promise we continue to live by!

> "…to know I have the support of Tony is amazing. I have given him my BUPA number etc in case I hurt myself and he needs to get me to a private hospital. I know that if ever I needed him he would be there and it takes so much stress away. I know Mum and Dad will also be able to relax a bit knowing that I have someone who really loves me and looks after me."
>
> (21/01/2013. Diary Entry. 1 year 9 months post diagnosis*)*

Social support from friends took the form of my Gym Buddy 'Laura' who started to come to the gym with me to help me with my motivation.

> "My first 6 week block of training went really well. I have a training buddy and we both freely admit that every morning we look at our phones in the hope that the other has cried off so we can go back to bed! The mesSage is never there! We usually wake up at some point on a bike in the gym doing a warm up – although I have managed to do 7 mins on a bike, 7 mins on a cross trainer and 3 mins of 7 on a treadmill before my brain has clicked into gear and I realise where I am. My training buddy and I have completely different goals. She wants to be skinny. I want some bone density. In most of our sessions we warm up together and then split up to carry out completely different exercises…but the fact that she is there makes it so much easier."
>
> (16/08/2011. Blog post. Four months post diagnosis)

Interactions with 'Others'

In terms of social relationships with others with the condition, I found that I was reticent to the extreme to read about their stories and journeys as for me, it made my own diagnosis more real.

> "I was on the NOS website...[and] looked at the forum. It completely freaked me out! I only two posts – 1 was from a woman of 45 who broke her hip skipping over and her T-score is the same as mine and another lady had 5 vertebral fractures in 2.5 months! Completely freaked me out, want to cry, panic rising, can't deal with it. Science I can deal with, facts, numbers etc but actual people talking about actual fractures completely freaks me out."
>
> (09/02/2012. Diary entry. Ten months post diagnosis)

When invited by the NOS to be an Ambassador for one of their bone health awareness campaigns I was to attend a launch event with another ambassador. I had been emailed prior to the event with some information about him so as not to upset me on the day as he presented with multiple complex issues with osteoporosis being just one element. As the event drew closer, I became more upset at the thought of meeting him.

> "What on earth am I doing?! I don't want to meet other people with OS because that's not me. I can't face that reality for my future – it's just not an option for me, fills me with terror, heart stopping, breath catching terror. What am I doing actually deciding to meet him [another ambassador with OS]. I am in idiot."
>
> (13/09/2017 – Diary Entry – 1 year 5 months post diagnosis)

This event, however, was incredibly humbling as I saw the true extent of the implications of having osteoporosis as a result of other serious health conditions. I also came face to face with my worst fear, spinal fractures:

> "Any other fracture site and I'm a bit non plus about it but I guess the spine is the ultimate incapacitation and vulnerability. Other fracture sites you can look at and see. The spine is your very core. If your spine fractures then that's it…the condition has got you and penetrated your very being. It literally terrifies me. I cried proper fat tears today. I did the event. I hated it when it was announced that I was there "if anyone wants to know what it's like to live with this crippling condition?"!!! I cried all the way home."
>
> (18/09/2012. Blog Entry. 18 months post diagnosis)

Meeting others with the condition, in a more severe form than mine was incredibly upsetting. It also made me feel as if I had been making a lot of fuss about nothing. Aside from my bone density, I was healthy and I felt after this encounter that I should be more grateful for that.

Reflection Five: Impact on a Physical Activity Lifestyle

Relationship with the Gym

As a hockey playing young girl and a gym user from my early 20s, I had always enjoyed physical activity. I always used to enjoy the gym. It was my escape from the world, and it made me feel strong, I loved the atmosphere, I loved the feeling afterwards, I loved the music. My relationship with the gym was beginning to waiver by August 2011 (4 months post diagnosis). At that point, I found every gym session was just a reminder about my bones because my rib lump stuck out through my T-shirt and the whole gym seemed to be one big mirror with an arrow pointing to it.

> "It's crazy isn't it that even when I know that going to the gym could effectively impact on my future health, wellbeing and mortality and I still couldn't be arsed to go!!!"
>
> (16/08/2011. Blog post. Four months post diagnosis)

> "I don't want to have to go to the gym. I used to enjoy going but now I HAVE to to try to gain some bone density and I think of 1000 excuses daily of why I'll go tomorrow instead."
>
> (05/10/2011. Diary Entry. Six months post diagnosis)

The gym was, instead of a place to forget all of my worries, now a representation of my skeletal fragility and cause of stress in its own right. I particularly struggled six months post diagnosis, perhaps due to the adrenaline of the diagnostic journey having finally worn off, or perhaps due to the realisation that my future lay only in my hands at this point as no other treatment was indicated, and that pressure was too much. Ultimately the one place of peace I had in my world at that time, was no longer a peaceful place for me.

> 'I think about it [my low bone density] every morning when I am making up my excuse not to go to the gym – then if I do go to the gym I think about it as it adds pressure to my sticking to my programme!'
>
> (05/10/2011. Diary Entry. Six months post diagnosis)

> "I seem to have reached a new level of gym apathy, which I have never really experienced before! I just can't get into it but have finally twigged why! The gym used to be my escape…and by 'used to be', I mean 'pre-diagnosis.' I would leave the world at the door and go and train. My training was fairly unstructured. I did what I felt like on the day! Sometimes weights, sometimes sprints, it really didn't matter to me as the main purpose was to just get fitter and develop a butt like one of the 'Reef Girls'! But now I HAVE to go. I HAVE to go and therefore I am now rebelling and don't want to go! I can't be bothered to get up and go early in the morning. I definitely can't be bothered to battle with the 'post work CV' bunch as the place is heaving from 5-7pm and so I can't get on any of the equipment I want to anyway! Now the gym has become something I have to do to try and increase my bone density. It is structured. It is specific. It is now boring and a constant reminder of the fact I have stupid bones and I need to go to the gym to try and fix them. Because of this it is no longer an escape from the world. It is a magnifying glass over the one aspect of my life that I want to just forget about and escape from. It particularly doesn't help that the mirrors and lighting there only go to exaggerate the shadow on my T shirt where my broken rib sticks out of my chest….a permanent reminder….one which, if someone would offer to remove it, I would be eternally grateful!"
>
> (10/10/2011. Blog post. Six months post diagnosis)

With varying degrees of commitment, I continued to go to the gym on and off for the next year, but my commitment waned once more, in the months after my foot stress fracture.

> 'I've lost confidence in training – I used to know exactly what to do and loved it but fracturing my foot earlier in the year has really knocked my confidence.'
>
> (30/10/2012 – Diary Entry – 1 year 6 months post diagnosis)

Finally, I rejoined the gym in December 2012 and started going on my own. I had found that going with 'Laura' was making me resentful that I was spending my time helping her reach her goal of trying to lose weight when in fact that was the last thing in the world that I was trying to do. By training on my own at this point, I found myself able to train at my own pace, focusing on exercises that I wanted to do, without the distraction of having to emotionally support someone else yet again over looking after myself.

> "I've re-joined the gym as a student! I love it. It's so much better training on my own (without 'Laura')…It means I can do what I want, when I want and I

> love, love, love, it. I've been going loads and having a fab time! I reckon that's why I feel on top of things – I've got my ownership back!"
>
> (30/12/2012. Diary Entry. 1 year 8 months post diagnosis)

I met my husband in that month (December 2012), and we started to train together when work allowed. It was such fun and something we continued to do until I was nine months pregnant with our daughter (March 2015).

Trust in the Body

Through the diagnosis of osteoporosis, I found that I had lost the unknown trust that I had previously had in my body. Following the diagnosis, I found that I went through acute stages of increased vulnerability in relation to physical activity and my risk of fracture.

> "I can't even go ice-skating with my niece and nephew without full body bloody armour. How many 33 year olds think "yey let's go iceskating, oh, what happens if I break something." It's shit."
>
> (29/12/2011. Diary entry. 8 months post diagnosis)

I knew that I wanted to keep physically active however and tried to push any fears of fracture to the back of mind.

> "I have decided that any activity is better than none so have cycled to work today and I almost went for a run the other day (was more a trot but at least I was outside!)"
>
> (10/10/2011. Blog post. Six months post diagnosis)

Ironically the activity that caused my first ever fracture (my scaphoid fracture in January 2010) became an escape from worrying about hurting myself further. Protective equipment is actively encouraged in snowboarding, and as such, I did not feel in any way alienated from my peers when I hit the mountain with 80% of my body covered in protective armour! The trip in January 2012 also kick started my love of the gym once more.

> "So I went snowboarding, had an amazing time, didn't fall over that much and loved being active every day! Since then I have been back in the gym 5 days a week and it was just a change in mind-set that got me there. I used to use the gym for stress relief but as soon as I felt I HAD to go (to do strength training and get some bone density back) it became a stressor in its own right! I have developed a well-honed tactic for dealing with stress over the last 20 years … AVOIDANCE! So I started avoiding the gym. After snowboarding I decided just to get back to being active and enjoying the gym so have spent the last few weeks training with a friend and whilst I know the stuff I am doing is not proven to increase bone density I am building back up to a 6 week block of specific strength training, which HAS been proven to slightly increase BMD in time for my DEXA scan in a few months! …. Now THAT will be an interesting time!"
>
> (23/01/2012. Blog entry. Nine months post diagnosis)

Random periods of vulnerability still struck every now and then as if to remind me when I had forgotten for a period of time that there was vulnerability present within my body.

> "Mountain biking with friends! So much fun but first time in ages I've had the scared feeling in my tummy that I am scared I'm going to hurt myself and it literally makes me want to cry when it hits….I just had a teary panic that if I fell over I might break something – I couldn't let myself go. I was sad, resentful, trying to hide it from my friends but felt so vulnerable – I hate it, hate it, hate it."
>
> (17/08/2012. Diary Entry. 1 year 4 months post diagnosis)

Reflection Six: A Stranger in a Biomedical Land

Both my experiences with the medical profession and my information seeking as an educated patient, combined to highlight how much of a stranger I was within both the academic literature and the biomedical world of osteoporosis. To be labeled with any condition has huge implications for one's processing of a diagnosis. To be labelled with a condition that has such a marked cultural stereotype that is so divergent from your own presentation, was something I found particularly isolating. This isolation was two-fold. I was a stranger to my diagnostic group in that I was 30 years younger than the more traditional demographic for the condition, yet I was

also now a stranger to my peer group as I was negotiating feelings, fears and practicalities of a much older person.

A Stranger to my Diagnostic Group

At the start of my journey, I initially isolated myself from patients featured within literature as I felt I was in no way comparable with their situation. I actively avoided using the terms 'osteoporosis' and 'patient'.

> "That's another thing. I'm NOT a 'patient'. I have found myself referring to me and other women as patients but hang on I don't want that label! I'm not taking medication, I'm not undergoing ongoing treatment. I'm a strong, active female NOT a patient. It implies reliance and weakness, and I refuse to have either."
>
> (09/02/2012. Diary Entry. Ten months post diagnosis)

> "I hate the label 'patient'. I hate the fact I, according to the NHS have osteoporosis – in my head that is a degenerative condition and I am not degenerative, I just happen to have low bone density and they should call it something else."
>
> (15/08/2012. Diary Entry. 1 year 4 months post diagnosis)

The more I read about osteoporosis, the more I realised that the term should never have been applied to me. The diagnosis of osteoporosis was for postmenopausal women who have accelerated bone loss. I was a premenopausal woman with low but stable bone density. I should have just been termed as having low bone density. The literature stipulating these delineations, however, had not filtered down to any of the original chiropractors, or subsequent GPs who were involved in my situation and as a result the label 'osteoporosis' has a permanent place on my medical records. These professionals simply did not know how to apply World Health Organisation guidance on osteoporosis to my population. I was merely attached to the more traditional demographic in terms of pharmaceutical prescriptions, yet these were wholly inappropriate and dangerous for my age group. The lack of filtering of information down into those within the NHS led me to seek a private healthcare route as I felt the NHS simply was not set up for me, a stranger in a biomedical population.

There were many occasions when my position as stranger was exposed or indeed challenged. When I attended a support group event in order to ask a consultant some questions, the welcoming committee asked me if I was attending with my grandmother. I recently presented at an appointment for a breast examination, and when asked if I had any other long-term health conditions I said I had low bone density and was classified as osteoporotic. The examining consultant stopped writing, looking directly at me and asked: "*Are you sure*?" Checking into Accident and Emergency reception when I had fractured my foot I told the desk I thought I had a foot fracture and was osteoporotic to which I received the reply "*No. Really? How did you get that then?*"

One of the most infuriating of incidences involved the delivery of a magazine sent out to those who have registered as members of the National Osteoporosis Society (NOS).

> "I came home to my copy of Osteoporosis News…but it came in a bag with 2 things which I just cannot cope with…1) Insurance you can rely on (Age UK). Improving Later Life – Insurance for the over 50s and 2) a health living brochure full of hearing aid cleaning kits, portable, adjustable sofa tables and an instant portable bidet! I'm 33! Oh, my good god, I've just found the adult full size meal protector and bladder control underwear! Now I know the common demographic is the over 50 but come on! Even those up to 65-70 would be insulted by the advertising sent through the mag! My mum is 63 and is in no way in need of any of that crap…it's so insulting/upsetting/unnecessary. It makes me so angry and upset at the same time – how can they pigeon hole all members? Just 'cos we have fragile bones doesn't mean we have lost bladder control and all need corn plasters! The NOS is supposed to be on our side – but we are all pigeonholed once more."
>
> (10/03/2012. Diary Entry. 11 months post diagnosis)

For me, this supplement to the main magazine to which we had all subscribed would have made many women feel like strangers to their diagnostic group. Middle aged, yet fit, determined, women who were not defined by the label of their condition and who were not limited by fractures or deformities, living full and active lives were

being presented with such an extreme stereotype of the needs of those with osteoporosis that I am sure that supplement would alienate many women.

A Stranger to my Peer Group

Not only was I a stranger to my diagnostic group but by having a diagnosis for a condition with such a strong stereotype, I felt I was experiencing elements of life that were setting me outside of my peer group.

> "I am finding I am choosing my shoes according to their tread and whether I might slip over! I never used to care. I recently bought a new pair of boots and the deciding factor on which ones to buy was the grip on the bottom. I am 34 years old and choosing shoes according to the criteria old ladies use."
>
> (17/01/2013. Diary Entry. 1 year 9 months post diagnosis)

> "The uni car park is icy and it's nearly made me cry. I'm in trainers and it's slippy and I am scared of slipping over…I'm 34 years old and have worries in my head of someone double my age – it's not fair!"
>
> (21/01/2013. Diary Entry. 1 year 9 months post diagnosis)

I felt I was carrying burdens and thoughts that others my age would not even be considering at this point of their lives. I felt isolated by these thoughts and this isolation quickly led to resentment that I was in this position in the first place.

Reflection Seven: The Emotional Journey

I can only describe the emotional journey in the clichéd phrase of it being a roller coaster. My emotional state was linked to so many elements of my experience that it is beyond the capabilities of this section to encapsulate the entire journey, hence emotions are spoken of in many of these reflective sections. Within this section I reflect on the overall experience, trying to capture the range and depth of emotions I experienced and the contexts in which they arose. The second I realised that I had broken my ribs my life took a course I could never have anticipated. The emotional journey of that time was initially driven by fear and upset that my life would spiral in a way that would mean that I did not want to live it.

This is my life,
My new depth of reality,
Scared of myself and my own vulnerability.
Pain and plaster, worries and fears,
The latter the cause, but both bring fresh tears.
I don't want to have this life that I'm living,
I just want to relax, keep smiling and giving,
But I find I can't give; I've nothing left beyond me
I can't tell those who I love; this is not meant to be.
Futures are bright with love, hopes and dreams
But mine is uncertain, I'm scared and it seems
That no matter what, I will crumble and fall,
I will shrink and remember how once I was tall.
…Will I get worse if I nurture a child?
…Will I have to take pills and have all fractures filed
With the rest of my hopes for a healthy future
Stored on a database, on a hospital computer?

(04/04/2012. Diary Entry. 11 months post diagnosis)

My quest for information was to anchor my present to a specific element of my past to somehow explain the condition appearing in my life. I was almost grieving for a future that I felt I would now never have. My information seeking then directly caused a whole range of further emotions as what I read caused me to feel anger, frustration and upset over researching causes and starting to piece together how my years at school and their continued impact into my 20s could have potentially caused my life to change so markedly.

> "I feel like I am living with a fricking black cloud over my future and I don't want to acknowledge it, give it the time of day, think about it anymore than I have to. I am angry I have got it. I am angry that I can't just be fucking normal and not continually be fighting anxiety and bone issues. That's the joke really. I suffer with anxiety – perhaps the contributing reason for why I am in the state I am – yet now I have found out what state I am in, I am now fighting increased levels of anxiety! It's a vicious, vicious circle!"
>
> (05/10/2011. Diary Entry. Six months post diagnosis)

The overriding feeling throughout the whole period of diagnosis to two years post diagnosis was one of fear. Fear over what my life might look like in the future, fear over not finding anyone to love me with this condition, fear and hopelessness of ever being able to get rid of my low bone density and the feeling would strike if ever I allowed myself to remember that this was actually happening to me.

> "What happens if I can't get rid of this completely? Will I definitely get osteoporosis post menopause? Oh it's all a bit real today and I don't like it."
>
> (30/10/2012. Diary Entry. 1 year 6 months post diagnosis)

This fear was punctuated by intense flashes of anger. Once causative factors were established, and it became obvious my past had directly affected my present health, I was so angry. Angry at the bullies who caused me such pain. I wanted to contact them, but I didn't.

Walking out of the final consultation with the specialist in London, where I had been told I was not degenerating and should just take action at the menopause I was elated. My fears of rapid degeneration had somewhat been addressed and I felt as if I had control over the situation for the first time.

> "…So this combined with the fact that my osteoclasts are functioning normally means it doesn't appear as if I am prematurely degenerating or ageing….I just never really grew up properly in the first place by not fulfilling

> my peak bone mass potential!... This made me really happy! I have another scan in 2 years and with all being well I won't be degenerating and so can just deal with postmenopausal bone loss as and when it happens with a nice bit of HRT!"
>
> (12/07/2011. Blog Post. Three months post diagnosis)

But within weeks I would be feeling overwhelmed or angry or frustrated – a whole range of emotions that were ultimately caused by an overwhelming fear that my future would not be healthy or happy. Anger at the cause of my condition would rear its head spontaneously. This anger would then lead to realisation that this was actually happening to me and that would cascade into fear and hopelessness.

The common thread was that if I distracted myself from my own feelings enough, I was coping. If the distractions lessened at any stage, I found myself overwhelmed with worry and uncertainty about what this condition would actually mean for me in the years to come.

> "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 months (from rib fracture to my final London appointment) my life was scans, tests, waiting for blood test results, 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."
>
> (10/10/2011. Blog post. Six months post diagnosis)

Uncertainty was directly linked to the silent and invisible nature of the condition. Unlike other chronic conditions such as diabetes, for example, low bone density and osteoporosis has no feedback method as to one's condition other than DEXA scans. These are not indicated for any more frequently than every two years due to the radiation that they involve. This lack of knowing, uncertainty as to the condition of my skeleton, not knowing if I was degenerating further, preyed on my mind a great deal. As someone who likes to be in control and have all the information I need to hand, this unknowing was particularly difficult to reconcile.

> "I've started thinking quite a lot about my next scan. I know there is a margin of error with them so I don't want to have one too soon and demotivate myself but then I do want to know if it's getting work (my BMD that is). It's so scary. What happens if my BMD is worse? Maybe it'll just be the error of the scanner – maybe I'll then regret having a scan too early – maybe I should wait longer?"
>
> (28/01/2012. Diary entry. Nine months post diagnosis)

> 'My consultant from the [London Hospital] was in the [National Newspaper] today talking about pregnancy induced osteoporosis, and so adding another layer of worry to me about my future! So I seem to remember someone telling me you can't be DEXA scanned during pregnancy and I know I am starting with a low BMD so does that mean my bones might get even worse if I become pregnant?! Why is there no information out there about this stuff and why hasn't my GP sat me down and spoken to me about all of these considerations, rather than just try and prescribe me bisphosphonates (which the …[London hospital}… told me a shouldn't touch with a barge poll as I haven't had children – and then I shouldn't touch them anyway!)
>
> (07/02/2012 – Blog post – 10 months post diagnosis)

To try to gain control over my emotions I would undergo a series of minimization moments when I would aim to reconfigure the nature of the condition to match another that I had, that caused me no issues at all, that of being short sighted.

> 'Maybe I should just think of it as having glasses! It's just part of me - I am short-sighted and it might get worse with age but I don't know for sure so no point in worrying about it!'
>
> (09/02/2012. Diary entry. Ten months post diagnosis)

> 'I often compare my bones to being short sighted. It's just one of those things and the only reason it is causing me angst is because I know about it! '
>
> (01/08/2012 – Blog post – 18 months post diagnosis)

To have objective confirmation that I had improved my skeletal bone health between my first and second scans led to a euphoria that lasted a good few weeks. The previously invisible had become visible once more and in a positive and motivating way.

> "The relief is overwhelming …Mum and Dad are so pleased! I almost feel a bit of a fraud though. It almost devalues the pain of the last year – like I am worried people will think that I've made a big deal about nothing."
>
> (02/07/2012. Diary Entry. 1 year three months post diagnosis)

In the more turbulent of emotional times, however, I wondered whether it actually served me any purpose knowing that my bone density was low. To know something about your body, but to have no regular objective means of monitoring your condition was particular hard for me, and I questioned whether it was worth knowing in the first place.

> 'It turns out I have changed my mind – I wish I never knew I had this stupid thing – it causes me panic, absolute blind panic.'
>
> (09/02/2012. Diary entry. Ten months post diagnosis)

[Following my most recent DEXA scan (outside of the date parameters for this study) one year post-partum (2016), in which I learnt that my bone density was now lower than it had ever been) I made the decision that I did not wish to have any further bone scans. I felt that knowing my T-score only led to an emotional vulnerability and journey that ultimately served no purpose, and as such I have decided to live my life happily, with bone health in mind but without it becoming anything that will affect my general state of mental wellbeing].

When the invisible became visible once more, my reaction was extreme and caused me to question my entire future. Eighteen months post diagnosis I got a stress fracture to my left foot - A fracture that was attributed to my osteoporosis. To have a third presentation of my bone health through fracture in two years spiraled me into a depression, a sadness, a feeling of complete hopelessness and fear over a rate of fracture that, if it were to continue, I would find unsustainable.

> "God I'm scared. I feel vulnerable and scared and I don't want this in my life. I wish I didn't know. That foot fracture has really knocked my confidence."
>
> (30/10/2017. Diary Entry. 1 year 6 months post diagnosis)

The process of recovery from that fracture was more mental than physical. It affected my confidence in the gym, my confidence in my hopes for my future and I

had lost my ability to reassure others that I was okay. I felt I had come so far in terms living with my low bone density to have such an obvious reminder of the potential for my future just made me despondent and overwhelmed once more.

4D. Chapter Summary

Through a reflective analysis of the life as experienced, seven reflective themes have been presented. These were: Engagement with the Medical Profession; Information seeking and the Educated Patient; Managing Invisibility and Disclosure; Social Interactions; Impact on a Physically Activity Lifestyle; A Stranger in a Biomedical Land; and The Emotional Journey. Throughout each of the themes, reflection and raw data from diary and blog entries have been used together, in order to answer the research question, How have I, a young active female, experienced living with premenopausal osteoporosis?

Osteoporosis is a condition that is biographical in nature. It is the experiences during bone formation in adolescence that can impact on one's bone health in adulthood. To reflect this natural history, an autobiographical approach has been used within this chapter to provide the reader with both context and experience, through the presentation of Part One: A Life Experienced and Part Two: Reflections on Experience. The reflective themes of Part Two are discussed in relation to the broader literature on chronic illness, in the next chapter.

CHAPTER 5: DISCUSSION

5A. Introduction

The preceding chapter provided the story of the life as experienced through the diagnostic journey and the reflective topical autobiography of the life told in order to answer the research question, How have I, an active female, experienced living with premenopausal osteoporosis? Seven themes of this experience were explored through the use of diary and blog data excerpts collected at the time of the experience. With each of the first six themes having a direct impact on the emotional journey, the experience of living with premenopausal osteoporosis is summarised in the schema below:

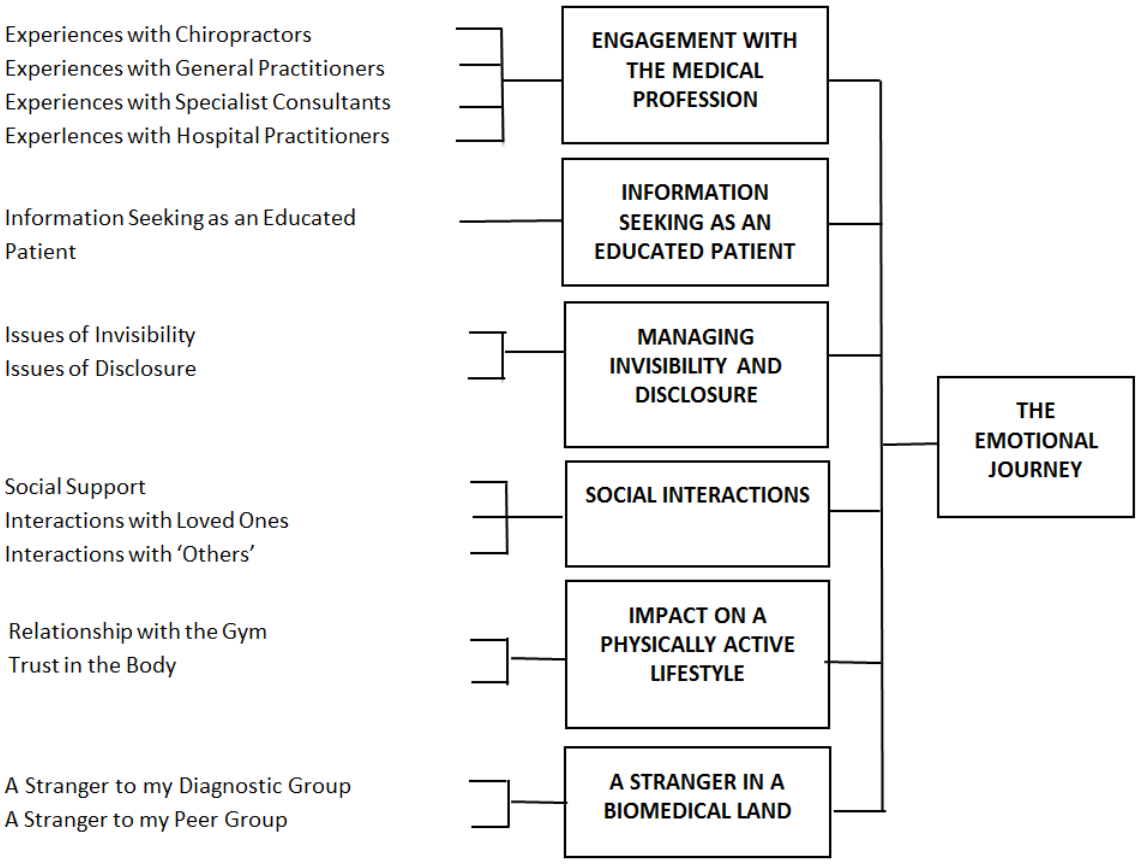


Figure 4: A schema summarising the findings from this present study exploring the experience of living with osteoporosis, as a young, active female.

Each of the seven reflective themes evident within this autobiographical study, had elements that mirrored those experiences expressed by others with osteoporosis, as

presented in the literature review in Chapter Two. The emphasis of each reflection however differed from those experiences of more traditional population on postmenopausal females. Within the literature review, the theme of Information Seeking was a subtheme of Engagement with the Biomedical Aspects of Osteoporosis (see Chapter Two, section 2B). Information seeking, within the findings of this present study, was found to be such a strong component that it was reflected upon as a theme in its own right and so separated out from the biomedical engagement section of Engagement with the Medical Profession. Within the literature review, Physical Activity was a subtheme of Adapting to Living with Osteoporosis however in this present study the theme was again addressed separately as being a strong component in its own right. The reflection on being A Stranger in a Biomedical Land had no corresponding literature within the main literature review although it is acknowledged that the section on Non Traditional Populations (Chapter Two, section 2F) does discuss this element of experience in relation to males with osteoporosis. The following table demonstrates the themes generated from articles included within the literature review and their relationship to the related reflections generated from this present study.

Themes generated from articles included in the literature Review	**Related reflections generated from this present study**
Engagement with the Biomedical Aspects of Osteoporosis	Engagement with the Medical Profession
	Information Seeking as an Educated Patient
Social Implications of Living with Osteoporosis	Social Interactions
Adapting to Living with Osteoporosis	Impact on a Physically Active Lifestyle
The Emotional Journey through Osteoporosis	The Emotional Journey
	Managing Invisibility and Disclosure
	A Stranger in Biomedical Land

Table 8: A table demonstrating the relationships between themes generated from the literature review and reflections produced within this present study.

To avoid mere repetition of the detailed analysis of patient experience literature presented in Chapter Two, this chapter will take each of the reflections of Chapter Four, Part Two and discuss the main themes both in relation to the literature on osteoporosis but also in relation to the broader literature within chronic illness. Care must be taken, however, when comparing patient experience literature across chronic conditions. Each condition has its own profile of symptom burden, visibility, pharmaceutical load and impact on the individual's daily life. To compare the experience of a person with high symptom visibility and daily burden, to that of someone with the silent condition of osteoporosis, would not necessarily serve to accurately portray the issues and implications of living with this condition.

Literature used within this Discussion, therefore, has been chosen to include those studies that focus on the patient experience of those with invisible chronic illness conditions. The table that follows presents the systematic reviews used with the discussion.

Author	**Chronic Illness at the Focus of the Study**
Sim & Madden (2008)	Fibromyalgia Syndrome
Yu et al. (2008)	Chronic Heart Failure
Hopp et al. (2010)	Chronic Heart Failure
Hueso-Montoro et al. (2012)	Qualitative meta-study including 15 different chronic conditions
Culley et al. (2013)	Endometriosis
Sutanto et al. (2013)	Systemic Lupus Erythematosus
Caldwell (2014)	Haematological malignancy
Disler et al. (2014)	Chronic Obstructive Pulmonary Disease
Green et al. (2014)	Chronic Venous Leg Ulcers
Li et al. (2014)	Type II Diabetes
Smith et al. (2014)	Osteoarthritis
Garcia-Sanjuan et al. (2016)	Crohn's Disease
Nakayama et al. (2016)	Systemic Sclerosis

Table 9: Systematic review studies included within the discussion

The following table lists the single studies of the patient experience of silent conditions used within this discussion.

Author	Chronic Illness at the Focus of the Study
Cunningham & Jillings (2006)	Fibromyalgia
Andersson et al. (2008)	Prediabetes and Type II Diabetes
Arnold et al. (2008)	Fibromyalgia
Hadert & Rodham (2008)	Osteoarthritis
Olshansky et al. (2008)	Type II Diabetes
Denny (2009)	Endometriosis
Seear (2009)	Endometriosis
Rodham et al. (2010)	Fibromyalgia
Brosh (2011)	Epilepsy
Kneck et al. (2011)	Type II Diabetes
Raty & Wilde-Larsson (2011)	Epilepsy
Clark (2012)	Endometriosis
Kneck et al. (2012)	Type II Diabetes
Rutberg and Ohrling (2012)	Migraine
Moore (2013)	Ulcerative colitis
O'Hara et al. (2013)	Type I Diabetes
Al-kalemji et al. (2014)	Asthma
Kao & Tsai (2014)	Osteoarthritis
Lafarge et al. (2014	Charcot-Marie-Tooth Disease
Yorke et al. (2014)	Pulmonary Hypertension
Johansson et al. (2015)	Type I and Type II Diabetes
Sammut et al. (2015)	Ulcerative colitis
Snape (2015)	Epilepsy

Table 10: Single studies of patient experience in invisible chronic illnesses used within this discussion.

5B. Engagement with the Medical Profession

A patient's health care journey will, usually, involve some interaction with the medical profession. The reflections presented in Chapter Two: Part Two of this present study demonstrated that the experience of engagement with the medical profession in this instance was variable. The experiences were polar in nature with positive experiences with specialist consultants but feelings of frustration, dissatisfaction and ultimately a loss of trust in the medical profession below the level of specialist consultant were evident. The negative feelings experienced within this present study do not appear to be unique. Inconsistent experiences have previously been reported in a number of osteoporosis patient experience papers (Roberto and

Reynolds 2001; McKenna and Ludwig 2008; Hallberg 2010; Solimeo et al. 2011; Weston et al 2011; Besser et al. 2012; Nielsen et al 2013; Hansen et al 2014).

The negative experiences within this present study were associated with a feeling of knowing more than the medical professions, a lack of continuity in care and a lack of practitioner knowledge in relation to premenopausal osteoporosis as a condition – leading to a general feeling of frustration. Similar feelings were also reported by those with postmenopausal osteoporosis (Hallberg 2010; Besser 2012; Hansen et al. 2014; and McKenna and Ludwig 2008). In fact, feelings of frustration and disappointment at the lack of knowledge demonstrated by their professionals in relation to their conditions, have been reported in patient experience literature across a number of chronic conditions (Cunningham et al. 2006; Arnold et al. 2008; Seear et al. 2009; Rodham et al. 2010; Brosh et al. 2011; Kneck et al. 2011; Kneck et al. 2012; Rutberg et al. 2012; Kao et al. 2013; Al-Kalemji 2014; Lafarge et al. 2014; Yorke et al. 2014). Patient frustration has been shown to develop most commonly from the communication style adopted by the medical profession, who focus on the objective biomedical data associated with the condition, with little discussion about how the diagnosis might impact on the patient's experience of life from diagnosis forwards (Cunningham et al. 2006; Kneck et al. 2011; Kneck et al. 2012; Al-Kalemji 2014; Yorke et al. 2014).

Those with chronic health conditions have been shown to desire open, information appropriate dialogue with specialists in their conditions (Yu et al. 2008; Hopp et al. 2010; Hueso-Montoro et al. 2012; Culley et al. 2013; Sutanto et al. 2013; Caldwell 2014; Disler et al. 2014; Green et al. 2014; Li et al. 2014; Garcia-Sanjuan et al. 2016; Nakayama et al. 2016). Specialist nurses have often been commended (Green et al. 2014; Garcia-Sanjuan et al. 2016) but feelings of a lack of respect, support and understanding from doctors (Culley et al. 2013; Li et al. 2014; Garcia-Sanjuan et al. 2016); missed symptoms or symptoms not taken seriously/trivialised (Culley et al. 2013; Sutanto et al. 2013; Nakayama et al. 2016); delays in diagnosis (Culley et al. 2013; Garcia-Sanjuan et al. 2016); a lack of information about their condition and prognosis (Hopp et al. 2010; Hueso-Montoro et al. 2012; Caldwell 2014; Disler et al.

2014; Li et al. 2014; Garcia-Sanjuan 2016) have all been directed specifically at General Practitioners and Consultants.

Whilst these feelings towards General Practitioners were mirrored in this present study, the specialist consultants who were sought out privately, were a lifeline to acceptance, information, trust and a feeling of hope. The feeling that consultants traditionally see the more advanced, clinically concerning, atypical patients in their areas of specialism within the National Health Service (NHS) led to the meetings with the two consultants that provided a normalisation to the experience. They were armed with the experience and resources to instil a knowledge-based calm to their consultations. The specialist consultants within this present study were the only ones to acknowledge the psychosocial impact of the diagnosis, rather than merely the biomedical one. Honest and empathetic communication with doctors has helped patients counter the fear of their diagnosis (Nakayama 2016) and this was the case in this present research.

A lack of trust in any profession below that of specialist consultant was apparent within the reflections presented in this present study. This lack of trust stemmed from both a previous experience of mismanagement of a fracture (the wrist break in January 2010) and a feeling of knowing more than each of those professions about the condition in question. Trust in one's medical team has been shown to be important in a number of chronic illness experiences, with an expectation that they will give accurate and, most importantly, personalised information about the patient's condition (Yu et al. 2008; Hopp et al. 2010; Hueso-Montoro et al. 2012; Culley et al. 2013; Sutanto et al. 2013; Caldwell 2014; Disler et al. 2014; Green et al. 2014; Li et al. 2014; Garcia-Sanjuan et al. 2016; Nakayama 2016). Only the specialist consultants gave personalised information in this present study. Trust appears not to be the common experience and a lack of trust has been shown to leave chronic illness patients feeling powerless, abandoned, confused, frustrated and angry (Yu et al. 2008; Hopp et al. 2010; Hueso-Montoro et al. 2012; Culley et al. 2013; Sutanto et al. 2013; Caldwell 2014; Disler et al. 2014; Green et al. 2014; Li et al. 2014; Garcia-Sanjuan et al. 2016; Nakayama 2016). Trust in one's medical team has

however been shown to give individuals a sense of control when faced with uncertainty (Caldwell 2014). Trust and respect have both been shown by Sutanto et al. (2013) as being directly linked to adherence to treatment as a sign of respect towards the prescribing clinician.

Finally, in multiple chronic conditions, patients have been shown to have felt they were left to co-ordinate their own care between health care departments (Kneck et al. 2011). They have felt they were just given medication and then left to their own devices (Al-Kalemji et al. 2014). This experience of abandonment and patient driven follow up was also evident within this present study: Blood tests, follow ups, DEXA scans, consultant appointment were all patient driven in this case.

The negative experiences of both those with osteoporosis and those with other chronic conditions mirror those expressed as dehumanising elements of the conceptual framework for the dimensions of humanisation (Todres et al. 2009). This value framework was presented as a spectrum of possibilities as a base for guiding care. The eight elements serve as a standard to "judge the humanisation of care" (Todres et al. 2009, p. 69). Positive humanisation values are presented along with how these values may be obscured by a dehumanizing emphasis as outlined below.

Forms of Humanisation	**Forms of Dehumanisation**
Insiderness	Objectification
Agency	Passivity
Uniqueness	Homogenisation
Togetherness	Isolation
Sense making	Loss of meaning
Personal journey	Loss of personal journey
Sense of place	Dislocation
Embodiment	Reductionist body

Table 11: The conceptual framework of the dimensions of humanisation (Todres et al. 2009, p.70).

From the literature on patient experiences of osteoporosis, combined with the reflections within this present study, it can be seen that for many the communication style, information exchange, and objectification experienced through engagement with the medical profession, that the patient experience of osteoporosis is often a largely dehumanising one. In the instance of the premenopausal experience, this dehumanisation was exacerbated through the lack of knowledge about the condition evident in each professional below the level of specialist consultant.

5c. Information Seeking as an Educated Patient

Information seeking presented as a strong reflective theme within the patient experience of living with premenopausal osteoporosis. The process of information seeking evolved through time. Initially information seeking was both a desperate attempt to educate oneself on the biomedical aspects of the condition (due to the lack of knowledge presented by the medical professional), and to seek a cause. This process transitioned into reading the information from a practitioner perspective to work on treatment of the condition. Over time, information seeking became a drive to explore, and raise awareness of, the noticeable gaps in the literature in acknowledging both the condition itself and the idiographic nature of chronic illness experiences. Much of this emphasis on information seeking was due to the patient's previous biography impacting on the current diagnostic situation. This was in relation to both "local and societal contexts" (Erben 1998, p.7) making the patient both an *expert patient* and an *educated* one.

The traditional societal expectation that the doctor should be the medical expert, set against the feeling that the medical profession lack knowledge of a specific condition has been well documented in chronic illness literature (Cunningham et al. 2006; Arnold et al. 2008; Seear et al. 2009; Brosh et al. 2011; Rutberg et al. 2012; Kao et al. 2013; Lafarge et al. 2014; Yorke et al. 2014). The relocation of medicine from a revered self-protecting power, to an "open and accountable culture" (Bleakley 2013, p.27) is the result of a number of factors: the admission that there are high levels of

uncertainty within practice, leading to high levels of medical error; increased litigation for medical error; high profile cases, for example, GP murderers and hospital scandals; and a move to control medicine from the profession to government (Bleakley 2013). The move to patient centered healthcare (Department of Health 2010) has made a significant impact upon medical dominance, supported by the ease of access to medical information on the Internet and by patient support groups (Bleakley 2013). Patients are now able to information seek and driving their own health care journey.

Yu et al. (2008) reported that collaborative care was needed to recognise patients as experts on their own lives so that their individual characteristics are observed and recognised within the long-term treatment plan. A drive to patient centred care and terms such as the "expert patient" (Department of Health 2001, p.32) have been embedded within the values of the NHS for a number of years and stem from the Government's White Paper, *Saving Lives: Our Healthier Nation* (Department of Health 1999). The concept of the expert patient acknowledges the findings of health care professionals that those with chronic conditions "understand[s] their disease better then I [they] do" (Department of Health 2001, p.5). Whilst the expert patient is one who is the expert in their own life, the term *educated patient* has also been coined within this present study to describe a person with a biography that presents as a cognitive ability and availability of resources to information seek on a deeper level than that which is available to the lay person. With BSc and MSc degrees in the field of musculoskeletal sports injury assessment and management, and through currently working within a Higher Education Institution, the information seeking processes was enhanced through previous professional knowledge and current access to extensive literature searching resources.

An element of the initial information seeking behaviour, was to try to anchor the diagnosis to a specific cause. The process mirrored that presented by Bury (1982) in his work exploring chronic illness as a biographical disruption.

> "In searching for the meaning of events, answers to questions – why me? why now? Incidents from the past are set against presumed knowledge of the disease's causation" (Bury 1982, p.174).

In this present study, the knowledge of the causation was not *presumed* but deeply researched within biomedical literature in order to establish the risk factors for the non traditional presentation of osteoporosis in a premenopausal female. The information seeking on causation also directly resulted in many of the emotional elements of the experience of living with the condition. This was particularly with relevance to the preventability of the condition and known risk factors being missed by the medical profession over the previous 15 years. (The emotional journey is discussed in section 5H of this chapter).

Those with osteoporosis have previously been found to understand the risk factors for the condition but unable to situate the condition within their own biography of risk factors (Besser et al. 2012). Similarly these individuals could not reconcile how they could have prevented the condition from developing (Hallberg 2010; Solimeo et al. 2011; Sale et al. 2012). Much of the information seeking reported in postmenopausal populations with osteoporosis was through means such as television, the internet, support groups and the National Osteoporosis Society (Roberto and Reynolds 2001; McKenna and Ludwig 2008; Nielsen et al. 2013). Information sought by the patient themselves was often used, as in the case of this present study, (in seeking out a parathyroid consultant), to allow the asking of specific questions of medical professionals (Paier 1996; McKenna and Ludwig 2008).

Similar to the findings within this present study, taking on the status of educated patient through personal research can both reduce and compound the stress of the condition (Culley et al. 2013). A desire and need for information has been shown to be a careful balancing act between seeking information in order to understand a condition, particularly in the cases where patients felt that their doctors did not provide enough clear information (Hopp et al. 2010; Caldwell 2014; Disler et al 2014) and feeling overwhelmed by either too much information, or the nature of the information received (Caldwell 2014; Nakayama et al. 2016). Patients have reported

feeling that the information they did receive was catastrophised (Al-Kalemji et al. 2014; Johansson et al. 2015). This was very much the case in this present research when the diagnosis was accompanied but the comment *'You could die from osteoporosis'*. Medical information has been shown to focus on worst case outcomes, without any consideration for the impact of resultant limitations would have on the patient's quality of life (Al-Kalemji et al. 2014). Too much information has been seen as overwhelming and scared patients (Al-Kalemji et al. 2014; Johansson et al. 2015). Furthermore if that information was seen as ever changing, complex and contradictory (Seear et al. 2009; Kneck et al. 2011; Kneck et al. 2012), patients wanted even more information about their condition in order to increase their technical knowledge (Seear et al. 2009) and develop strategies to incorporate it into their lives (Johansson et al. 2015).

There appears to be a fine line between seeking information to help with coping and positive living and receiving too much information and experiencing the negative consequences that the situation initiates (Cunningham et al. 2006; Arnold et al. 2008; Seear et al. 2009; Brosh et al. 2011; Rutberg et al. 2012; Kao and Tsai 2014; Lafarge et al 2014; Yorke et al 2014). Within this present study each of these implications was deemed to be true. Information was sought as part of the coping process but the information seen led to wholly negative experiences that directly impacted on the emotional journey of living with the condition of premenopausal osteoporosis.

5D. Managing Invisibility and Disclosure

For those with osteoporosis the manifestation of the condition can range from no visible signs to severe spinal curvature and fracture episodes (Hallberg 2010). In this present study the condition has moved from invisible to visible through three fracture episodes and three DEXA scans, with each episode initiating a strong emotional reaction. The impact of osteoporosis being a predominantly silent and invisible condition, presented in the findings of this present research, in a number of ways: Anxiety and frustration at the lack of objective regular bone density

measurement to assess bone mineral density; acute upset and fear when the invisible became visible through fracture; and the issue of disclosure of the condition to others. Each was strongly associated with elements of the emotional journey (discussed further in section 5H of this chapter). Previous patient experience studies have shown that when invisible, the condition of osteoporosis is a minor part of the person's life (de-Souza et al. 2010; Weston et al. 2011). Similar to the findings of this study however was that when the condition did become visible through fracture, acute sadness was felt, accompanied by fear over the potential degeneration in bone health status (de-Souza et al. 2010; Hallberg 2010; Weston et al. 2011).

The reflection on invisibility (see Chapter Four, Reflection Three) highlighted the negative emotional impact of not being able to monitor the condition regularly or know bone health status at any given moment, due to the lack of presentation of symptoms. This desire for monitoring and objective feedback has been linked to feelings of control over a condition (Andersson et al. 2008; Kao and Tsai 2014; La Farage et al. 2014; Johansson et al. 2015). For those for whom this level of control was not possible, for example those individuals with osteoarthritis or epilepsy (and premenopausal osteoporosis as evident in this present study), there were feelings that the condition had control over the individual, rather than the other way around (Kao and Tsai 2014; Lafarge et al. 2014). For those with a new diagnosis of the invisible condition of diabetes for example, going through the learning process of regularly testing their blood sugar levels was a way in which they could gain control over their condition and control over their daily lives (Johansson et al. 2015). Because the condition was now essentially under the control of the patient at home, they felt that they could relax and be one step ahead of their illness (Andersson et al. 2008; Kneck et al. 2011) reducing their anxiety and promoting relief, increased security and control (Kneck et al. 2011). The meter allowed patients to test themselves discretely to give them the reassurance that all was well (Kneck et al. 2012). Patients reported how they tended to test more when they were first diagnosed through fear that they did not know what their blood sugar was, and as an attempt to gain control over the uncertainty their diagnosis had caused them, but

once they were more used to their body's reaction to stimuli they found they tested themselves less and less (Kneck et al 2011).

With osteoporosis, no such measurement tool is available. Consequently, individuals must wait for two-year periods between DEXA scans to get an objective marker for their bone health. They are unable to access the therapeutic benefits, reported by those with portable blood sugar meters for diabetes, of knowing the status of their condition. Within this present study the wait for both initial and follow up scanning proved to be incredibly difficult. The lack of objective quantification of bone health led to feelings of fear, panic, and a desperate need to know if self-led interventions were working. It also led to frustration when being asked questions by colleagues about how the condition was progressing etc. Not being able to respond with any facts led to further feelings of frustration and agitation. When a second scan was completed the positive feedback gained from an increase in bone density provided a huge emotional high equalled only in intensity by the low following a third scan that showed that postnatal bone density was lower than ever before. The emotional impact of knowing bone health status was reflected upon and ultimately it was decided to be an unnecessary element of the emotional journey of living with premenopausal osteoporosis in this case. With no intervention known, at this point in the life course, to improve bone mineral density, the impact of monitoring and perhaps receiving further bad news was one that was now going to be avoided. Despite the negative experiences reported above, there are also benefits of invisibility in that the patient can forget about their condition (Li et al. 2014; Smith et al. 2014). This was also an element of reflection in this present study. Individuals with osteoporosis have previously found it hard to reconcile having a condition with no symptoms or presentation (Weston et al. 2011; Besser et al. 2012; Hansen et al. 2014).

Without symptoms to attribute their condition to, some patients with chronic conditions, such as those with endometriosis (Culley 2013) found processing their new status as *patient* particularly difficult – The same could be said for those with a diagnosis of osteoporosis who are yet to fracture (Barker et al. 2016). The benefit of

invisibility in terms of forgetting the condition has been the case in the findings of this study but it must also be acknowledged that it is hard to separate the positive effects of invisibility, from the healing effect of time since diagnosis. One element however that was strongly linked to the emotional journey, and reflected upon in the present study (see Chapter Four, Reflection Three) was the psychological impact of the invisible becoming visible once more, through both the rib fracture presentation and the foot stress fracture.

The visibility of the rib fracture through clothing was a regular reminder of a poor bone health status that caused emotional pain, upset and fear of a physically vulnerable future. The stress fracture to the foot led to an acute emotional reaction that presented as profound sorrow at the perceived loss of a healthy future. Each fracture marked a step back in terms of both health and the emotional journey (discussed more fully in section 5H of this chapter). A physical representation of the condition brought the diagnosis to the forefront of consciousness once more. Barker et al. (2016) completed a meta-ethnography of patients' experience of osteoporosis that resulted in the formulation of a conceptual model incorporating cultural constructs, gender (stigma) associations and physical manifestation of the condition yet call for more research of homogenous groups of participants with osteoporosis to gain further insight (Barker et al. 2016). The model focuses on the visibility and invisibility of osteoporosis symptoms and how that drives the patient experience

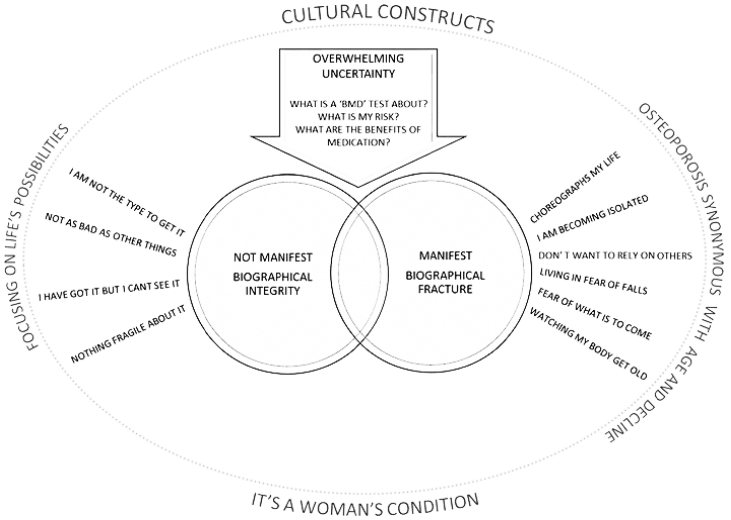


Figure 5: A Conceptual Model for the Patient Experience of Osteoporosis (Barker et al. 2016, p.33)

Within the model, invisibility leads to the patient's biography being *intact* whilst those who have fractured or have another physical manifestation of the condition, for example, an excessive spinal curvature (or in the case of this present research a new fracture or visible deformity from fracture healing), have a *fractured biography* in which they watch their body ageing before its time.

Beyond the implications of invisibility reflected upon for this present study, invisible nature of other chronic conditions has been shown present further social considerations. Individuals with an invisible chronic condition have been shown to have a fear of not being believed and having to justify why they are acting in a certain way or are concerned about certain things, as they look well to observers (Hadert and Rodham 2008; Rodham et al. 2010; Lafarge et al. 2014; Yorke et al. 2014). A feeling of no one appreciating the patient has a condition that requires their mental energy (Yorke et al. 2014) and the importance to the patient of feeling understood and having their condition acknowledged by others, has caused frustration, dismay, and patients turning to online support groups to validate that they were not fabricating their condition and concerns (Hadert and Rodham 2008; Rodham et al. 2010). A lack of visible signs and symptoms has been shown to cause a general lack of acknowledgement of a condition by friends, family and the medical profession with some being told that they "don't look sick and just like to be ill" (Arnold et al. 2008, p.118). There appears to be a deep desire to be believed, but patients with invisible conditions report feeling doubted, with the fear of not being believed leading to a feeling of shame (Rutberg and Ohrling 2012). The emotional burden felt by patients, is exaggerated in those for whom there are no objective clinical diagnostic (such as in fibromyalgia syndrome) leaving them feeling that they must continually justify that they experience an actual condition (Rodham et al. 2010).

Patients have reported that when coping well emotionally with their condition, others forget that the individual may have issues, concerns or limitations at all (Kneck et al. 2011). The invisible nature of their condition can make it hard to get sympathy, recognition, and understanding from family member and friends

(Sutanto et al. 2013; Caldwell 2014; Nakayama et al. 2016). Certainly in this present study there was limited sympathy or understanding from a significant other ('Pete'), addressed more fully in the following section (Chapter Five, section 5E) concerning social interactions.

The nature of invisibility means that usually, it is the responsibility of the patient to decide when and how to disclose their condition to others. Many patients have reported a desire to hide their condition unless disclosure is absolutely necessary (Rodham et al. 2010; Rutberg and Ohrling 2012; O'Hara et al. 2013; Al-Kelemji et al. 2014; Yorke et al. 2014; Johansson et al. 2015). Within this present study the decision to disclose the condition or not, was seen as an element of control. The blog was deliberately anonymous and served as a platform to provide insight, comment and information without disclosing the author. Any decision to disclose the diagnosis was a personal one. To have that control taken away, in the incidence of disclosure by the University, led to acute feelings of anger and betrayal that the disclosure was being treated so flippantly, when the condition was having such a profound impact on everyday life.

The small number of chronic illness patients to speak of the importance of disclosure has included those with epilepsy, diabetes and pulmonary hypertension (Raty and Wilde-Larsson 2010; O'Hara et al. 2013; Yorke et al. 2014). Those with epilepsy have spoken of the importance of disclosure to decrease the fear of seizures amongst family, friends, and colleagues. It was also found that this group of patients also avoided situations where disclosure might be necessary (Raty and Wilde-Larsson 2010). By not disclosing their condition, patients have felt they are seen by others as *normal* (Yorke et al. 2014) thus avoiding any stigma associated with their condition. Those with diabetes and younger patients with pulmonary hypertension, for example, have reported the issue of preconceptions and stigma associated with their conditions, stating that they did not wish to disclose their condition especially it they were young, old or overweight (O'Hara et al. 2013).

Young patients, such as these have been seen to want to avoid judgement or discussion over their misplaced position within their diagnostic group, stating that they look healthy and so the assumption is they should be able to do all the things young people do, but cannot (O'Hara et al. 2013). This could also be the case for premenopausal women as osteoporosis has such a strong stereotype. Patients with asthma or migraine have avoided disclosure, unless symptoms were particular severe/noticeable, as they were worried about being seen as less capable than their colleagues due to their condition (O'Hara et al. 2013). Those with fibromyalgia syndrome have been shown to attempt a veneer of normality in order to manage the perceptions of others. This had the added benefit to this patient group of feeling that they were not giving in to their condition (Rodham et al. 2010).

Whilst each condition has its own unique reasons for disclosure, the emergent evidence is that those with invisible conditions wish to keep them invisible for fear of disbelief, judgement, and stigma (Arnold et al. 2008; Rodham et al. 2010; Brosh et al. 2011). This is especially evident for those conditions such as fibromyalgia syndrome where this is still disbelief, amongst some, that the condition exists (Rodham et al. 2010) or where there is a general lack of public awareness of a condition (Arnold et al. 2008) (also the case for premenopausal osteoporosis). Non-disclosure allows patients to maintain an external representation of normality and to distance themselves from their condition but raises questions over when should one disclose their condition to new partners and new people (Brosh et al. 2011). This worry over disclosure to new partners was a concern reflected upon in this present study. The fear of knowing when and how to disclose the diagnosis and the implication for what the future may look like together, was of particular concern when a new long-term partner was met. The support offered by this new partner however, served to decrease the importance of the diagnosis once more, due to their understanding and acceptance.

5E. Social Interactions

The reflection on social interactions (see Chapter Four, Reflection Four) demonstrated a complex web of interactions that were brought to light, as a result of the diagnosis of osteoporosis. Interactions with loved ones involved primarily protecting them from knowing the true depths of emotional pain that were being experienced. Having always been protective of loved ones there was a concerted drive to place their emotional wellbeing at the forefront of the journey. Hiding feelings for the sake of others has been reported in patient experience literature of other chronic conditions with those patients feeling that they needed to protect their family from the condition by hiding their own feelings and withholding prognostic information (Hueso-Montoro et al. 2012; Caldwell 2014). Similar to the findings in this present research, those with osteoporosis have found the impact is both on familial and social levels, with physical presentations of the condition and worry about fracture impacting on both areas of the individual's life (Paier 1996; Roberto and Reynold 2001; Hallberg 2010; Neilsen et al 2011)

Chronic conditions have been shown to impact both positively and negatively on both social and personal interactions (Yu et al. 2008; Hopp et al. 2010; Hueso-Montoro et al. 2012; Culley et al. 2013; Sutanto et al. 2013; Caldwell 2014; Disler et al. 2014; Garcia-Sanjuan et al. 2016; Nakayama et al. 2016). Reliance on family for emotional and physical support has been seen to be a cohesive process for all (Yu et al. 2008; Hopp et al. 2010; Hueso-Montoro et al. 2012; Li et al. 2014). Where individuals within the osteoporosis patient experience literature, have struggling with losing their family care-giver role due to manifestations of their condition (Roberto and Reynolds 2001) family relationships have been a source of comfort, (Paier 1996; Roberto and Reynolds 2001; McKenna and Ludwig 2008; Hallberg 2010; Besser et al. 2012).

Within the literature associated with other chronic health conditions, some patients had noticed that their family were coping with their diagnosis by avoidance of any discussion about it (Caldwell 2014); whilst others felt that their family were smothering them (Nakayama et al. 2016) and expressing concern when all the

patient wanted to do was forget about the condition (Caldwell 2014). This later point was echoed by Sutanto et al. (2013) and Li et al. (2014) who reported that patients felt family were over intrusive and over protective, which exacerbated the patient's feelings of losing control over their lives. Patients with no visible symptoms, however, have reported feeling a lack of support from family, and for female patients with care giver roles within the home, they felt they were still having to put others wellbeing before their own (Li et al. 2014).

Partners of those with osteoporosis have been shown to provide practical and emotional support (Paier 1996; Roberto and Reynolds 2001; McKenna and Ludwig 2008; Hallberg 2010; Besser et al. 2012). Some partners have been accused, by their significant other, of being overly worried about them and their potential to fracture (Roberto and Reynolds 2001). Conversely in this present study, the diagnosis served as a magnifying glass to an already strained relationship with a partner. Issues that were within the relationship prior to the diagnosis were now magnified, with the partner refusing to offer any reassurance, comfort or support for what was seen merely as a genetic weakness. Patients from a number of chronic illness populations have also experienced rejection by partners and the dissolution of relationships with those who were unable or unwilling to be supportive (Caldwell 2014; Culley et al. 2013; Nakayama et al. 2016).

Engagement with other individuals with osteoporosis was a particularly difficult experience and reflected upon in Chapter Four, Reflection Four of this thesis. This difficulty was predominantly due to the fear of becoming how these other individuals presented. The fear was initiated not only by face-to-face meetings, but also from reading about the experiences of others with the condition (which were therefore avoided for many years). Hearing the experiences of others with osteoporosis has been shown to bring new fears about how one's own condition may progress and manifest in the future (Hadert and Rodham 2008).

The experience of visiting a support group was a particularly upseting event, due to being so much younger than any other member. The realisation that the presenting

bone density at that time was the same as those 40 years older, led to fear as to how low the bone density might be when older age was reached. Support groups for those with osteoporosis, are, for some, an enjoyable source of social support (Roberto and Reynolds 2001; Nielsen et al. 2011). For others however, similar to the findings within this present study, the group situation would mean that one might meet someone in a worse condition than oneself and this needed to be avoided so as not to experience increased fear for the future (Nielsen et al. 2011; Nielsen et al. 2013).

Social support groups for those with other chronic conditions have also been shown to be a divided experience (Yu et al. 2008; Hopp et al. 2010; Sutanto et al. 2013; Caldwell 2014; Li et al. 2014). Patients have reported a feeling of comfort in attending groups as it reminded them that they were not alone in living with their condition (Yu et al. 2008; Sutanto et al. 2013; Li et al. 2014) and that they were ways of staying connected to the world (Hopp et al. 2010). Talking with others has been shown to validate ones experiences (Hadert and Rodham 2008; Raty & Wilde-Larsson 2010; Al-Kalemji et al. 2014; Johansson et al. 2015). It enables newly diagnosed patients to gain confidence from others in their ability to live positively with their condition (Kneck et al. 2012).

This comparison with others in the same diagnostic group appears to go against the sociological literature supporting social comparison theory (Festinger 1954). Social comparison theory can be defined as the,

> "process of thinking about information about one or more other people in relation to the self" (Wood 1996, p.520).

Comparisons are predominantly made in an upward direction, that is, individuals tend to choose to compare themselves to those who are better off and place themselves in that category (Collins 2000). Downward comparison theory (Wills 1981), suggests that when self-esteem is threatened (as is the case when negatively experiencing a chronic illness) comparison changes to downward, to someone less well off than oneself, in order to restore self-esteem (Hakmiller 1966). With a diagnosis of a chronic condition, particularly one such a premenopausal

osteoporosis, social comparisons are complex. Upward comparison theory would suggest that the individual would compare themselves to others in their age group who do not have a chronic condition, and as a result the individuals self-esteem is affected negatively (Gerber et al. 2018). If the individual were to adopt a downward comparison, however, and compare themselves to someone worse off, (perhaps an individual with more severe osteoporosis) self-esteem is also negatively affected as the condition as the subject of the comparison is a reminder of the potential future the individual faces (Nakayama et al. 2016).

These notions of comparison were evident in this present study as represented as an inability to read other patient experience stories without extreme upset. Each of these stories was ultimately from a postmenopausal woman, fracturing, ageing and representing their experience in story form. When an individual is diagnosed with a condition associated with older age, whilst in early adulthood, it seems that any comparison with others only serves to cause increased fear and anxiety over the future presentation of the condition. This seems particularly true of osteoporosis when the cultural stereotype of healthy ageing is still one of deterioration and decline (Phoenix and Sparkes 2006). The comparison to such a divergent social group led to feelings of despair, hopelessness and avoidance of patient experience literature. Had a story been available from someone in a comparable group, such as a premenopausal female, the chaos narrative might have been calmed to one of restitution (Frank 1995).

Premenopausal osteoporosis has had a surge in public awareness in recent months (January to April 2018) due to high profile, female athletes, speaking out through social media, about their poor bone health due to overtraining, lack of menses and under eating (see BBC 2018 for examples). The telling of these stories can only help to provide comparable narratives to other premenopausal women allowing restitution to emerge through their chaos.

The cultural stereotype of ageing is discussed further in section 5H of this chapter.

5F. Impact on a Physically Activity Lifestyle

Within this study, the relationship with physical activity was shown to fluctuate throughout the data collection period. What was once an enjoyable activity of gym use became a burden to fulfil in order to be proactive in maximising bone health. Through the biography prior to diagnosis, knowledge of the benefits of physical activity to bone health were known and further explored through information seeking. Commonly physical activity is seen as osteo-protective (Senderovich and Ksomopoulos 2018). Studies have consistently found that weight bearing activity such a running, rather than non-weight bearing, for example swimming, have the most impact on the development of peak bone density (Guadalupe-Grau et al. 2009; Huang et al. 2017). It is the physical strain and load through the bone that has most impact on adaptive bone formation (Rubin and Lanyon 1984). No matter what form of weight bearing exercise is taken by young women for example jogging or resistance training, the mechanical loading of the skeleton has been shown to increase BMD in both the femur and lower back (Guadalupe-Grau et al. 2009).

With an active adolescence and early adulthood, (predominantly through playing hockey) it is clear that physical activity was not enough in this present study to help accumulate peak bone density. The menstrual status of the participants has been shown to be a major factor in the resultant osteogenic response to an exercise intervention (Nickols-Richarson et al. 2007; Guadalupe-Grau et al. 2009). Amenorrhoeic female athletes (average age 16) have been shown to not gain the same bone mass from impact sports participation as eumenorrhoeic females (Nickols-Richardson et al. 2007). The impact of events within the biography in this present study resulted in low peak bone density being achieved, despite being physically active.

Following diagnosis, the role of educated patient resulted in the self-prescription of a strength-training programme to systematically load the skeletal system and stimulate bone growth. Its success was evident in the second DEXA scan that reported significant bone growth in the femur. The literature on the patient experience of osteoporosis reports that many individuals with a diagnosis do not feel confident in taking part in exercise, for fear of doing something wrong (Hallberg

2010). A common feeling was that information from general practitioners was too vague, with physical activity being poorly endorsed by medical professionals (Paier 1996; McKenna and Ludwig 2008).

The drive to develop and complete a strength-training programme, was the realisation that any improvement in bone density would be a personal responsibility. Within broader literature, many individuals across a number of conditions have similarly reported feeling that it was their own personal responsibility to manage their own condition (Andersson et al. 2008; Raty and Wilde-Larsson 2010; O'Hara et al. 2013; Al-Kalemji et al. 2014; Johansson et al. 2015). Patients have re-evaluated former habits and have had to decide on how they would live in the future (Andersson et al. 2008). Similarly the awareness of negative triggers or risk factors for exacerbation of chronic conditions has been reported by patients as being their responsibility (Raty and Wilde-Larsson 2010; O'Hara et al. 2013).

This personal responsibility has been seen by some, as having been externally and unwittingly imposed on them (Johansson et al. 2015). This has manifested as an all-consuming burden and obligation that is resented on some levels (Johansson et al. 2015). This reaction was present within this current study and the relationship with going to the gym. A once enjoyable activity to reduce the stresses of daily life, the gym became a treatment for poor bone health and a stressor in its own right. Resentment, both within this present study and in those with other chronic conditions has been shown to stem from the realisation that efforts would never lead to a cure for their condition but the responsibility to look after oneself and greatly added to daily stress (Seear et al. 2009). A feeling present within this present study and reported in wider literature was a feeling of wanting to hand over this responsibility to someone else, rather than feeling they had to do it all on their own (Andersson et al. 2009; Seear et al. 2009). Some of the negativity towards going to the gym demonstrated within this present study stemmed from resentment, the visibility of the rib fracture and the impact of a training partner causing distraction from the primary goal of bone building (as she wanted to only do exercises to lose weight). Further negativity stemmed from the ambiguity within osteoporosis

literature leading to a lack in confidence in knowing exactly what exercises would ultimately prove to be the best for increasing bone mass.

There are a number of research studies that report on the impact of different exercises on bone density (see Bornor et al. 1988; Beck et al. 2017; Mack et al. 2017; Rafiq et al. 2018 for examples). There is no body of literature to support the notion of appropriate exercises for different T-scores. An homogenistic approach is taken through the grouping together all those with a T-score less than -2.5SD as being osteoporotic and so needing to avoid particular exercises for fear of fracture. This approach was evident in the patient support event visited within the first month post diagnosis in this present study.

5G. A Stranger in a Biomedical Land

Through the process of engagement with the medical profession, the information seeking experience, the issues around managing the invisibility of the condition and the impact on social interactions, the implications of being a biomedical stranger became apparent. These implications impacted directly on the emotional journey experienced and expressed within this present research study. Very quickly in the patient experience of living with premenopausal osteoporosis, the notion of being situated outside of the traditional demographic for the condition, was represented. The GP stated that most of his patients were older and that he did not know how to treat the condition in a young woman. This feeling of being a stranger to a diagnostic group was exacerbated with each medical interaction where the health professionals were not aware of causation, the implications of bisphosphonate medication or the psychosocial implications of being diagnosed with osteoporosis at the age of 33 years old. The journey of stranger-hood, started due to the NHS using diagnostic criteria for the condition that had previously been questioned within research. The recommendation is to term those premenopausal females with a T-score <-2.5SD, as having low bone density, rather than osteoporosis. Despite the incorrect application of a diagnostic term acting as a catalyst for each event that followed clinical investigations, reactions from others and lack of definitive

treatment plan, all served to exacerbate the feeling of now being a stranger, not only to the diagnostic group, but also within ones peer group.

The only other non-traditional group with osteoporosis to be researched has been males with the condition. The feeling of being a stranger to the diagnostic group was strongly reported within their experience stories (Solimeo et al. 2011; Nielsen et al 2013). The feeling was predominantly due to the strong stereotype associated with the condition being predominant in the older, postmenopausal woman. Males reported that the diagnosis brought to their awareness a feeling of non-inclusion in the biomedical information and support materials available to them. The postmenopausal female image was predominant in each of these aspects of their experience, the result of which was a feeling that none of the information applied to them as they were stronger, less frail and a different gender to the demographic to which all information was directed (Solimeo et al. 2011; Nielsen et al. 2013).

The concept of "stranger" was proposed by Simmel (Simmel and Wolff 1950, p.402) and describes the notion of a wanderer who finds himself in a group that he has not belonged to from the beginning. In the context of this present study, the stranger is the premenopausal woman who finds herself now within a diagnostic group populated by postmenopausal women. The same application of the concept would be made for males now finding themselves in a diagnostic group for osteoporosis. There is "nearness" to the group through the commonality of the diagnosis yet at the same time "remoteness" is also evident through the demographic differences (Simmel and Wolff 1950, p.402). There is indifference, yet, also an involvement (Simmel and Wolff 1950, p.403). The realisation that only general features are in common between the stranger and members of their new group, only serves to highlight all that is not common – reinforcing to the stranger, how much of a stranger they are in that group.

> "The stranger is close to us, insofar as we feel between him and ourselves common features of national, social, occupational or generally human, nature. He is far from us insofar as these common features extend beyond him or us,

> and connect us only because they connect a great many people" (Wolff 1950, p.405).

Exley and Letherby (2001) explored this concept within the context of individual's experiences of biographically disruptive diagnoses of terminal illness, involuntary childlessness and infertility.

> "In one respect they [those with terminal illness, involuntary childlessness and infertility] remain part of the same group and sub-groups they always have, and yet they also occupy the position of a 'stranger' because their experiences place them outside the boundaries of those around them" (Exley and Letherby 2001, p.114).

Two representations of being a stranger are evident in this present study: Being a stranger to ones established social group, and being a stranger to a new group of those with osteoporosis. The feeling towards the established social group of young, active people, was that one was now having to process imagery, emotions and implications that others in that group did not have to face. This was a particularly emotional experience and reflected upon in Chapter Four, Reflection Six. There was a feeling of still being part of that group (nearness) yet feeling that there was now a lack of relatability to the daily concerns of that group (remoteness). As a young active woman, surrounded by young active people socially; within the academic role working on sports degrees; and having also had a professional career in elite sport, to now be mentally and emotionally processing a diagnosis synonymous with premature ageing and its associated implications, was isolating. Wanting to join in activities such as ice-skating or mountain biking, yet fearing falling and fracturing, made one feel set apart from the seemingly carefree decision making of peers. These feelings of isolation, driven by feeling different from mainstream society, have been shown to be exacerbated further by the individuals avoiding activities they previous enjoyed prior to their diagnosis with a chronic condition (Olshanksy et al. 2008). The reflections in this present study support these findings.

The second representation of the status of *stranger* was the feeling of being thrust into the social group of those with osteoporosis, yet not belonging to that biomedical demographic. The nearness was the commonality of the diagnosis yet

the remoteness was in every other aspect of the experience, and the related health care journey.

Within broader literature there is a paucity of literature addressing the experience of living with conditions for which the participant is a stranger to their diagnostic group, for example patient experiences of early onset Alzheimer's disease, males breast cancer or early menopause for example. The limited literature on the experience of those with early onset Alzheimer's disease, shows that these individuals and carers encounter existing structures and support programmes designed for older adults (aged over 65 years versus age 57.3 (SD=4.1) years in the Wawrziczny et al. (2015) study). This isolation from support through not feeling it is aimed at them is particularly difficult for carers who assume the role far earlier in their own life-course compared to carers of the more traditional demographic (Wawrziczny et al. 2015).

For those experiencing male breast cancer (Skop et al. 2018), the gender stereotype was strong, as it was in cases of male osteoporosis (Nielsen et al. 2011; Solimeo et al. 2011). Individuals with male breast cancer also reported a system established for female patients, where gender specific information was not readily available and where males felt out of place and awkward around female patients, when waiting for treatments in shared waiting areas (Skop et al. 2018).

In a study looking at early menopause in women aged between 23 and 46 years old (where the average age for menopause is 51 years old) the overriding themes was ones of premature loss, premature ageing and issues arising from medical interactions (Singer and Hunter 1999). These medical interactions repeatedly underestimated the psychological impact of the diagnosis and many diagnosed their own menopause having been "dismissed by doctors as being too young" to go through the associated hormonal changes (that were later confirmed as menopause) (Singer and Hunter 1999, p.72).

Of similarity to the experience of living with osteoporosis presented within this present study was a feeling of being out of synchrony with peers in relation to themselves as women. The imagery of a body that had rapidly aged as a result of cultural stigmatisation, was also in common with the present study. Females experiencing early menopause wanted to meet "those in the same boat" to somehow try and normalise their experience but these women needed to be as near as possible to their age, in the same situation (in having/not having children) as themselves (Singer and Hunter 1999, p.76). This peer support matching was also alluded to in this present study. Meeting those of similar age was an emotionally negative circumstance if that person presented with a more negative version of the condition. A more welcome source of support would be females as closely matched to the individual's presentation as possible to allow support without social comparison (discussed previously in section 5E of this chapter).

5H. The Emotional Journey

The emotional journey reflected upon within this present study was one impacted upon by each of the other topics of reflection. As a result, emotional aspects have been discussed within each of these sections but key elements are discussed further here. Subheadings have been used for ease of the reader in order to try to bring order to the chaos of the emotional journey.

Emotional Responses

The personal biography and position as a professional within sports injury management, combined with the position as an academic, and led to an intense phase of information seeking (previously addressed in section C of this Discussion). This information seeking was driven by a need to anchor the diagnosis to a specific causation, yet also caused a range of emotions from anger, frustration, fear, panic and a feeling of grieving for a life lost. Information seeking to attribute the diagnosis to a particular cause, has been shown to help individuals situate the chronic condition within their life-course, which in turn has helped with general acceptance of their condition (Caldwell 2014).

Feelings of loss are reported across a number of conditions within chronic illness literature: Loss of self, loss of a previous life, loss of hopes and dreams (Rodham et al. 2010; Brosh et al. 2011; Lafarge et al. 2014); a loss of relationship dynamic with one's spouse where roles have had to change in light of the condition (Rodham et al. 2010); and a general feeling of sadness as to how life has turned out (Rutberg and Ohrling 2012). Feelings of powerlessness and resignation that their condition would dominate their daily life experiences whether they were currently symptomatic or not have been shown to have a large impact on many patients (Yu et al. 2008; Hopp et al. 2010; Sutanto et al. 2013; Li et al. 2014; Nakayama et al. 2016).

The anger and frustration, felt during the diagnostic journey, were initially directed towards the school bullies that caused the anxiety in adolescence, and subsequent SSRI use (likely causes of the presenting low bone density). There was similar anger and frustration at the medical professionals who did not recognise or investigate the five separate risk factors for osteoporosis that presented within the biography from the age of 15 to 25 years old (low body mass index, anxiety, the late onset of menses, depression and SSRI use). A desire for medical hegemony and a passive sick role (Parsons 1951) was craved in order to feel looked after and confident in a positive outcome – yet neither were forthcoming. Anger and frustration were a representation of wanting to trust the medical profession but feeling unable due the previous experience of the mismanaged wrist fracture. This mistrust proved to be incredibly important in relation to the homogenised approach to medication taken by the GP (and recommended by other health care professionals throughout the journey). Information seeking and the specialist consultant in osteoporosis, each confirmed that for a premenopausal female, the taking of the prescribed bisphosphonate medication, could have catastrophic consequences should the patient conceive a child (Martinez-Morillo 2012). The drugs, designed to slow down bone making and bone making turnover, cross the placenta and the potential skeletal damage to an unborn foetus is unimaginable and echoes the thalidomide implications of the 1960's (Kim and Scialli 2011). The application of postmenopausal treatment protocols to premenopausal females demonstrated the homogenisation

of care that resulted in a dehumanising experience of health care (Todres et al. 2009).

Being labelled with the term osteoporosis was particularly upsetting due to the strong visual imagery the word conjured. Having learnt through information seeking that the recommendation for use of the word osteoporosis should have been reserved only for postmenopausal women and premenopausal females should be told they have low bone density (ISCD 2015), another intense anger response towards the medical profession was evident. The application of the correct/recommended terminology of low bone density could have potentially prevented many of the desperate moments of fear and panic associated with the personal imagery associated with osteoporosis.

Anger has previously been noted as a noticeable component of the grief response (Kubler-Ross 1969). Within the broader chronic illness literature, anger (Johansson et al. 2015), guilt at not doing enough to prevent the condition (Andersson et al. 2008); and grief at the loss of the life that could have been (Cunningham et al. 2006; Raty and Wilde-Larsson 2010; Brosh et al. 2011; Kneck et al. 2012; Kao and Tsai 2014) have all been reported. Some patients felt general increased anxiety levels as they felt trapped between the knowledge they were receiving regarding their diagnosis and the resultant lifestyle changes and the huge responsibility they now felt for their body – something that was both physically and emotionally demanding (Seear et al. 2009). Within this present study the feeling of responsibility for influencing positive change in bone density through exercise led to the complex relationship with the gym that was discussed in the previous section (F) of this discussion.

Uncertainty and fear were predominant emotions presented within the reflections for this present study as part of the emotional journey and were formalised within the poem written about the experience (see Chapter Four, Reflection Seven). These emotions have been shown to be common across all chronic illnesses following diagnosis (Yu et al. 2008; Hopp et al. 2010; Hueso-Montoro et al. 2012; Caldwell

2014; Culley et al. 2013; Sutanto et al. 2013; Li et al. 2014; Smith et al. 2014; Nakayama et al. 2016). The representations of uncertainty discussed in literature each align to Culley's (2013) classifications of diagnostic uncertainty, symptomatic uncertainty and trajectory uncertainty and each of these has been evident in the reflections for this present study.

Where patients have experienced a delay in diagnosis or the diagnostic process was a lengthy one (as in this present research) a huge amount of uncertainty is experienced by the individual as alternative diagnoses are systematically eliminated. In the case of this present study alternative diagnoses were bone cancer, a parathyroid tumour or early menopause. Uncertainty and fear about what life would now be like is a key cause of upset and concern (Brosh et al. 2011; Kneck et al. 2011; Kneck et al. 2012; Rutburg and Ohrling 2012; Kao and Tsai 2014; Yorke et al. 2014). Uncertainty of the future, fear of the unknown and uncertainty about rate of decline combines with a feeling of powerlessness over the condition, resulted in a general feeling of hopelessness and intense anxiety (Yu et al. 2008; Hueso-Montoro et al. 2012; Culley et al. 2013; Caldwell 2014; Li et al. 2014; Smith et al. 2014; Nakayama et al. 2016).

Uncertainty appears to be related to life stage (Brosh et al. 2011) with those being diagnosed with a condition in early adulthood (as in this present study) being more concerned about the impact of their diagnosis on their future (Hadert and Rodham 2008). This concern is with particular reference to traditionally anticipated life events such as having children (Raty and Wilde-Larsson 2010; O'Hara et al. 2013). Surprise and shock have also been shown to trigger a search for meaning, to answer the question 'Why me?' (Seear et al. 2009; Kao and Tsia 2014) – A reaction that was evident in this present study.

The reaction to the diagnosis within this present study contained particular emotional moments. The fear, uncertainty, perception of the condition and search for a cause, created an emotional reaction that was sustained until each element was addressed through either intervention or time. The main pathways of reaction to the diagnosis of a chronic condition and the subsequent adjustments which can

be summarised categories of patients presented by Yu et al. (2008): Those who felt imprisoned in an illness and so took a fatalistic approach about their condition and those who felt free despite their illness and took control of their condition. Patients feeling imprisoned following their diagnosis tried to avoid thinking about their condition, often trying to ignore their condition all together in a process of self-deception (Yu et al. 2008; Caldwell 2014); avoided talking about their condition with family (Caldwell 2014); felt shock and disbelief (Nakayama et al. 2016); and felt a lack of control and imprisoned by fear (Yu et al. 2008).

Individuals have been reported as having an existential awakening following diagnosis in which they felt the diagnosis had given them an opportunity to think about the meaning and purpose of their lives with an increased level of consciousness (Caldwell 2014). By placing their condition within the broader context of their lives, patients reported feeling fortunate to have the opportunity for their post diagnosis awakening so that they could appreciate life more fully, become more in tune with their values and priorities and take a path towards personal growth and spiritual transformation that fostered a feeling of empowerment and positive living (Hopp et al. 2010; Sutanto et al. 2013; Caldwell 2014; Disler et al. 2014; Nakayama et al. 2014). It is interesting to note however that those patients experiencing chronic illness towards the ends of their lives (>70 years old) (for example those in the Yu et al. (2008) and Hopp et al. (2010) reviews on coronary heart failure patients) were the predominance of those patients who saw the illness as a blessing, whereas those patients experiencing a condition in early to middle adulthood tended to find the diagnosis a far more negative process (such as chronic blood malignancy patients in the Hueso-Montoro et al. (2012) review) refusing to accept the chronic illness as their new life plan, avoiding thinking about both the future or their condition (Hueso-Montoro et al. 2012; Caldwell 2014).

Fluctuations between integration and separation from the chronic condition resulted in a new way of being, with patients referring to ‘the old me’ and ‘the new me’ in relation to their pre and post diagnosis selves (Kneck et al. 2012). In the reflections presented in this thesis terms such as pre-diagnosis and post diagnosis were often used to isolate moments in time and being. Similar to those presenting with other

chronic conditions, there was a desire to return to a pre-diagnostic self (Kneck et al. 2012) that represented a life where there was a reduced feeling of being different from peers (Olshansky et al. 2008).

Chronic illness literature has demonstrated how patients have a new found awareness of their body as a positive element of their lives; it had added new dimensions and new demands on their body which had to be listened to (Anderson et al. 2008; Seear et al. 2009; Kneck et al. 2010; Kneck et al. 2012). Listening and responding to this new awareness and experience of the body has been seen to be crucial for learning to integrate the chronic condition into the lived body (Kneck et al. 2012). A feeling of trusting that the body would react in the way that it needed to (Johansson et al. 2015) and that the individual could influence their body's functioning (Andersson et al. 2008) meant that individuals can find that if they look after their body in relation to their condition, they are also looking after their whole self (Kneck et al. 2012). This new found awareness can create a sense of responsibility for one's body, a sense of protective ownership where the chance to be nice to oneself takes primacy, with work and finances, for example, seeming less important (Seear et al. 2009; Kneck et al. 2011).

The new reality of a diagnosis, bringing with it new priorities and changes to the individual's lifestyle, have been shown to be positively interpreted as a "wake-up call" to action long term inaction (Kneck et al. 2011, p.561) for some patients. Within this present study the *wake-up* call was not necessarily associated with a personal awakening (as a healthy lifestyle was already being enacted) but more of an awakening as to the wider implications the personal journey had for society as whole. The quest for size zero, bullying within teenage years, the prevalence of anxiety, depression and SSRI use, all have negative impact on bone health status, yet no one was championing awareness of what could potentially be a hugely under-diagnosed condition of premenopausal osteoporosis. The anticipated increase in osteoporosis cases has recently been reported showing hospital admissions for osteoporotic fractures rose by 30% between 2000 and 2014, leading to a projected increase of 150% by the year 2046 (Kelly et al. 2018).

A means of coping evident within this present study was to minimise the diagnosis of osteoporosis through comparison. Having learnt that the correct diagnostic terminology should have been low bone density the go-to comparison was to my presentation of short sightedness (a feature of my biography since the age of 3 years old). The relabelling of the condition removed some of the fear of the stereotype of ageing with osteoporosis. Those with osteoporosis have often been seen to decrease the seriousness of their condition, usually by attributing fractures to other causes rather than their osteoporosis (Besser et al. 2012; Sale et al. 2012). Through reducing the seriousness of their condition within their worlds, patients moved away from thinking purely in terms of restrictions and started to personalise their approach to their condition to fit it in with their life and goals (O'Hara et al. 2013).

The main tool for reducing the seriousness of the condition was to use comparison against a more serious version of their own condition (Al-Kalemji et al. 2014) or other conditions the patient deemed to be worse than theirs (Brosh 2011), for example, fibromyalgia patients grateful that they do not have cancer (Cunningham et al. 2006). Patients reported not wanting to use up medical appointments in case someone who needed more help might require the time with the doctor (Al-Kalemji et al. 2014).

Patients from other chronic illness groups have been shown to also have a tendency to actively reduce the seriousness of their condition by moving away from a medical focus on their health and focusing on short term goals (O'Hara et al. 2013). For diseases without a visible presence, for example type 2 diabetes, patients reported that the only reminder that they had the condition was their insulin reading and as such their condition was a *disease* not an *illness*. This message is explored in the work of O'Hara et al. (2013) in their paper on patient experiences of type II diabetes entitled "It's not a disease, it's a nuisance". Once more this reinforces the potential impact of language and terminology on an individual's emotional journey.

Invisible conditions can become an annoying diversion of their attention but not a major part of the individual's life and could be worse (Kneck et al. 2011; Al-Kalemji et al. 2014). Patients reported not wanting to give in to their condition by giving it too much of their attention (Rodham et al. 2010; O'Hara et al. 2013) and a desire to live a normal life – just a little more carefully (Raty et al. 2010; Johansson et al 2015).

The impact of a chronic illness has been shown to be self-graded by individuals, not on their medical diagnosis or prognosis, but on the day-to-day impact their condition had on their individual lives (Al-Kalemji et al. 2014). Within this present research the impact was related directly to the possibility of fracture becoming visible to consciousness. The new mental clutter of evaluating fracture risk for activities, meant that the condition initially had a large impact – although this has diminished over time.

Life after the diagnosis of a chronic condition is never the same again (Andersson et al. 2008). The balancing of limitations with expectations (Cunningham et al. 2006) means there is a constant oscillation between prioritising a condition (for example being late for an event to return home to get syringes) and relegating their condition (by eating whatever they want). Changes were needed to create a desired life where the health condition was just one part that influences but is also influenced by, the individual (Kneck et al. 2012). For some, having a condition may have changed their lives for the better (Olshansky et al. 2008) in terms of lifestyle changes for example, but the patients still did not like that their lives had had to change in the first place. Patients wanted to live a life as normal but also that was best for their condition (Kneck et al. 2012).

A patients' desire for normality to resume was evident across a number of chronic illness papers (Sutanto et al. 2013; Caldwell 2014; Disler et al. 2014; Green et al. 2014; Li et al. 2014; Smith et al. 2014; Garcia-Sanjuan et al. 2016) with the want to live a *normal* life being facilitated by emotional and physical support in some cases (Sutanto et al. 2013). Whilst some patients struggled and wanted to maintain normality and adapt to their new lifestyle (Garcia-Sanjuan et al. 2016), some feel a

normal life has been lost to them (Green et al. 2014). Patients reported the process of living as a chronic illness patient mentally and emotionally draining, feeling that they had forever lost control of part of their lives (Li et al. 2014). Trying to accept their condition and live life day to day (Disler et al. 2014), maintaining hope and normality through balancing defiance with acceptance (Caldwell 2014) and finding happiness in every-day activities (Disler et al. 2014) this quest for normality was often negatively affected by friends and family being overprotective (Caldwell 2014). For patients with osteoarthritis there was a refusal to give up on normality achieved by ranking their condition against those they perceived to be worse off, for example those with cancer in order to normalise their experience as merely part of the ageing process (Smith et al. 2014).

The unique social world and stereotypes of ageing

Within this present research, a personal stereotype that ageing is synonymous with debilitation, frailty, lack of mobility, and a lack of independence, impacted upon the emotional journey and was a direct result of the social work in which the individual is situated. The family has been traditionally seen as the primary site of socialisation (Hockey and James 2003). Because of this positioning, it is through our family that we come to know who we are and who we will be as we process through ageing (Phoenix and Sparkes 2006). Grandparents, in particular, are seen as a key reference against which we understand how life may be experienced "in and through an 'old' body" (Phoenix and Sparkes 2006, p.112). These pre-presentations of ageing are at the forefront of anticipated outcomes for our ageing and traditionally support the notion of a declining and deteriorating body that "lives with pain, weakness and limited mobility" (Phoenix and Sparkes 2006, p.113). This naturally reinforces a younger person's anxiety over ageing especially when diagnosed with osteoporosis - A condition that introduces the concept of premature ageing (Singer 1974).

People are living longer and whilst many remain independent, 82% of individuals aged 85 or more, have one of more long term health conditions (UCL Partners et al. 2014). As a result of these conditions, the older population is a high user of health care services, and it is this that influences how older people are perceived (Scammell

2017). It is the nature of being human to categorise people and things in order for us to be able to make more sense of the world (Barry and Yuill 2012), but using a single characteristic of older age results in the process of stereotyping elements such as time loss, decline and dependency (Age UK 2018). Those in the *older people* category then become defined by their *oldness,* and we lose sight of them as individuals. This stereotyping assigns a group of people to a category for which certain negative characteristics are assigned. So often ageing is confused with related but separate issues such as longevity and dependency (Goodman 2010). Our stereotypical assumptions about this group of individuals are unfair when many are contributing so much to society as grandparents, volunteers, ”guardians of expertise and wisdom” (Scammell 2017, p.177).

The baby boom generation (the leading edge of which was born in 1946) has a spending power estimated in excess of $2 trillion and have redefined retirement (Rheault 2006). A previous notion of a work free retirement into old age is now filled with continued working, leisure, travel and the change in retirement image to include “surfing and mountain biking, rather than playing shuffleboard” (Johnson et al. 2009, p.102).

As a result of the biographical experiences and familial presentations of ageing (particularly of grandparents) within this present study, ageing should have been seen as an opportunity to embrace new things, spend time with family and be active within the local community. The fear of the future and ageing would more accurately be described not a fear of chronological ageing but a fear of the body failing. So much of health profession training and training in the field of sports injury management addresses and supports the view that ageing is complicit in an increase in dysfunction that needs to be overcome (Eichberg 2000).

The most prominent *fear of the failing body* evident within this present research, was a fear of spinal dysfunction through incidences of osteoporosis related vertebral fractures. This “feared self” (Phoenix and Sparkes 2006, p.115) is based solely on the maternal grandmother’s presentation as a result of her osteoporosis (and age) over

the last six years. Her physical decline started aged 92, one year before the diagnosis on which this thesis is based. The fear of mirroring her deteriorating body fuels the image of the feared self in later life (Frank 1995).

Biographical work has been emphasised within gerontology through the suggestion that stories are important in order to provide counter-narratives to the dominant story in Western Society, the narrative of decline (Gullette 2004). As new images of older people start to permeate Western society, a new outlook on ageing is presented as one of a "chance for self-realisation and personal growth" where an "endless youth" can be enjoyed (Phoenix and Sparkes 2006, p.117). The image of our "preferred self" can overwrite the image of our feared self, where the mind and body remain "active, able and independent" (Phoenix and Sparkes 2006, p.115). Randall (2007, p.370) argues that concerning the process of ageing,

> "a narrative perspective is equipped to acknowledge the inescapably idiographic and interpretive elements that are entailed in being human and the intricate uniqueness of actual lives in time."

If there is greater diversity in the stories about ageing, and this diversity is made available, people will have different stories to draw on to fit their experiences and live differently if they so wish and as the needs of their circumstances emerge (Gullette 2004).

> "Age must be different for each. We may each die from being ourselves"
> Scott-Maxwell 1968, p.120 cited in Randall 2007, p.373)

5I. Issues with Modelling Chronic Illness Experiences

Receiving a diagnosis of a chronic condition is, for some, the start of a long journey to understand their condition and learn how to incorporate its management into their lives. For others, it is a culmination of years of uncertainty bringing relief and hope to the future through a confirmed diagnosis.

Emotional journeys were was initially studied and proposed by Kubler-Ross (1969), in the Stages of Dying model. This incorporated five stages - denial, anger, bargaining, depression and acceptance. This model was quickly adopted by counsellors and

other professionals to try to understand grief (Smit 2015) and has since been used to explore individual's reactions to a diagnosis of chronic illness (Ahlstrom 2007) due to the loss of an anticipated life-course (Bury 1982). Whilst some of the emotions presented in this model are evident in the emotional journey explored in this present study (most notably anger and depression) the linear approach to the emotional phases are not evident and have been the main criticisms of this model in literature (Gilbert 2012). The emotional journey presented in this present research fits most confortably with a model proposed by (Udry et al. 1997). Within this model the individual is expected to exhibit three general categories of responses: Injury relevant information processing; Emotional upheaval and reactive behaviour, and Positive outlook and coping. This present study has shown this pattern of responses as illustrated by information seeking behaviours, the emotions of fear, anger, panic and finally a reframing of the condition to minimise its emotional impact.

The complex process of journeying through emotions to arrive at coping and living positively with chronic illness has been conceptualised in a number of other ways (see Samson et al. 2008; Weinert et al. 2008; Deacon et al. 2013; Griffiths et al. 2014; Ambrosio et al. 2015 for examples) in order to:

> "…raise awareness of the concept of living with chronic illness…to assess the process in a correct and uniform way…..and to guide the development of instruments to measure how people live with chronic illness in community practice" (Ambrosio et al. 2015, p.2357).

Ambrosio et al. (2015) completed a concept analysis of living with chronic illness, determining that patients with chronic conditions need the five main attributes of acceptance, coping, self-management, integration and adjustment in order to achieve positive living with their condition. Griffiths et al. (2008) had also attempted to:

> "…develop a typology based on patient experience and not specific to one illness with the potential to enhance person-centred follow-up of those living with chronic illness" (Griffiths et al. 2014, p.513).

To explore the appropriateness of these models and their application to patient experiences, it is important to determine the methods from which these concept analyses or typographies have been constructed. The concepts within the Ambrosio et al. (2015) study evolved from primary and secondary literature. Some of the studies used within the formulation of the conceptual analysis were synthesis studies looking for specific constructs within primary literature on chronic illness experiences for example 'acceptance', 'fatigue' or 'self-management' thus presenting bias in the synthesis data towards the presentation of certain concepts from 'patient stories'. Furthermore within Ambrosio et al's (2015) study the concluded attributes were not overwhelmingly present within the patient experience literature with the attribute of 'acceptance' only occurring in 33% of the papers analysed, 'coping' being in only 25%, 'self-management' 55%, 'integration' 14% and 'adjustment' 53% - Conclusions have been made as to the pathway to positive living for chronic illness patients based on data from at most 55% of the papers analysed.

Whilst qualitative research honours any experience as being valid, the decision to then use those experiences to generalise and model to a wider population goes against the fundamental theoretical assumptions of the interpretivist approach within which these studies were carried out. The typology for chronic illness presented by Griffiths et al. (2014) was developed using only data from individuals with back pain or Type 2 diabetes. Both of these conditions have strong preventative lifestyle interventions, no automatic progression to ill health and no daily visible symptom burden for the patient to manage, yet the authors state that:

> "because the typology developed in our study included people with either back pain or type 2 diabetes it may also be applicable to other chronic conditions" (Griffiths et al. 2014, p.519).

This statement again dismisses the idiographic nature of chronic illness experiences. Singular accounts of illness cannot be summarised or collated with data from others, each particular person has their own story that has to be "respected and recognised and hailed as significant" (Charon 2012, p.2).

It has been seen already within the literature (Nielsen et al. 2011; Solimeo et al. 2011) that males with osteoporosis have a unique set of experiences as they sit outside of the traditional cultural paradigm for the condition. This exploration of the only other non-traditional group was long overdue in order to work towards a deeper understanding of how non-traditional patients might have to navigate experiences outside of the expected journey of traditional patient and develop this previous conceptual model (Barker et al. 2016) to include the premenopausal patient group. This present PhD study has highlighted that whilst a visible representation of the condition does indeed cause an element of Biographical Fracture, the uncertainty over the future, daily worries of falling, physical activity limitations and fear of prematurely ageing all serve to make the condition visible to the individual in their mind's eye, despite not being physically visible. The visibility/invisibility is once more an individual interpretation, and perhaps the interrelationships with the elements of the Barker et al. (2016) model are a little more complex than represented in their conceptual diagram (see section 5D of this chapter).

Having completed this PhD research process, and the extensive reading of patient stories across a range of diverse conditions from chronic obstructive pulmonary disorder (Disler et al. 2014) to chronic blood malignancies (Caldwell 2014) and osteoarthritis (Smith et al. 2014) attempts to group elements of an experience either to create a measurement tool, concept analysis/typology/monitoring/evaluation tool, appear to miss one key element of that experience: the impact of an individual's unique biography prior to diagnosis.

From the point of diagnosis onwards there are indeed a number of comparable experiences for those with chronic conditions: such as interactions with the medical profession; the impact of perceived visibility or invisibility of the condition to the individual; the impact on the individuals' daily life and preferred activities; and social implications. Each of these areas impacts on the emotional journey that the individual goes through as they adjust to their diagnosis and incorporate their condition into their lives. The results of this present study and the wider patient experience literature on chronic illness highlights that the journey experienced by any one individual (with their condition) seems to be utterly ideographic in nature.

The patient experience is moulded by the nature of a particular condition, being experienced by a particular patient, within their own unique social world at a point in time that represents their present status in their biography.

5J. Proposing a Biographical Approach to Health Care Practitioner Understanding of Chronic Illness Experiences.

As a young, fit, active and premenopausal female facing a diagnosis for which there is a strong patient stereotype, no specified health care pathway nor appropriate pharmacological intervention, a biographical approach has been taken to connect the time of diagnosis with the previous biography. We are biographical beings and incidences of chronic illness cause disruption to this biography. Bury (1982) first introduced the concept of a chronic illness diagnosis being a disruptive event to an individual's life course expectations (bringing into the individuals present the reality of pain and suffering often only seen as distant events in one's future). Bury (1982) spoke of chronic illness disrupting ones biography following diagnosis as there is a biographical shift from ones anticipated progression through life, with its chronological stages, to one that has deviated markedly from this path to an unknown endpoint (Bury 1982).

The focus of the Bury model has been from the point of biographical disruption looking forwards. In both the telling of the life told and the reflections on the life experienced within this present study, it is the individual's previous biography that has had most impact on their experience and emotional journey associated with their condition. An interconnected biographical approach to both the diagnostic journey and living with their chronic condition cannot be modelled in terms of providing anticipated trajectories or outcomes due to the idiographic nature of each of our biographies. "A life that is studied, is the study of a life in time" (Erben 1998, p.13). Therefore the study of a life experience is also a study of that experience situated in a life time. Patients have reported that their attitude prior to their illness

event has had more impact on their journey than the presentation of the condition itself.

Taking into account this biographical impact, the experience of premenopausal osteoporosis within this present study maps more closely with the literature and modelling of injury events in the sport literature, such as anticipating an individual's reaction to sustaining a sports injury proposed by Anderson and Williams (1988) than the chronic illness models of Ambrosio et al. (2015).

Through the acknowledgement that the individual has had experiences previous to the injury event, Anderson and Williams (1988) have accounted for a biographical approach to a disruption in one's biography, that of an injury. Within our biography, we have usually experienced a number of disruptions or adverse events that have caused development of our personality, outlook and coping resources.

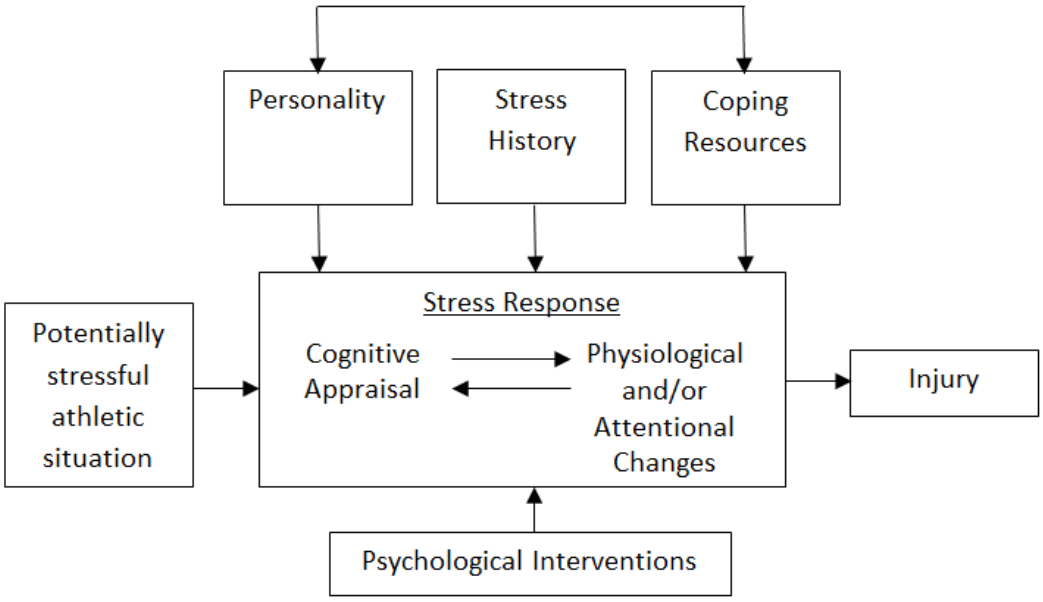


Figure 6: The Stress Injury Model (Anderson and Williams 1988, p. 297)

The model above demonstrates how the interconnectedness of one's past biography with one's present and ones future, can be anticipated and explored further in order to support each individual with moving forward positively along their life course.

In this present research, for example, the experience of bullying led to a coping mechanism of writing, a tendency to try to emotionally shut down and wait out times of upset. The bullying also led to a feeling of being an outsider. Each of these elements then reappeared in the biographical journey as the result of another adverse/disruptive event, the diagnosis twenty years later. Similarly an experience of fracture mismanagement prior to diagnosis played a huge part in the mistrust in the medical profession that coloured the experience of living with osteoporosis, a condition to which fracture is associated.

From the discussion within this thesis, it is very clear in that there are core experiences that transcend conditions, that is, experiences reported in almost all patient experience literature no matter what the condition: Interactions with the medical profession; Social Interactions; Sense making; and Perceived visibility of the condition. Each of these four elements directly impacts on the individual's emotional journey and their ability to positively live with their condition. This PhD research has also demonstrated that incidents in the individual biography prior to diagnosis can greatly impact on each of the four core experiential components mentioned above and so may ultimately also impact on the future biography and element of disruption that the individual experiences. It is from this view point that the biographical approach to understanding the idiographic patient experience of a chronic condition is proposed.

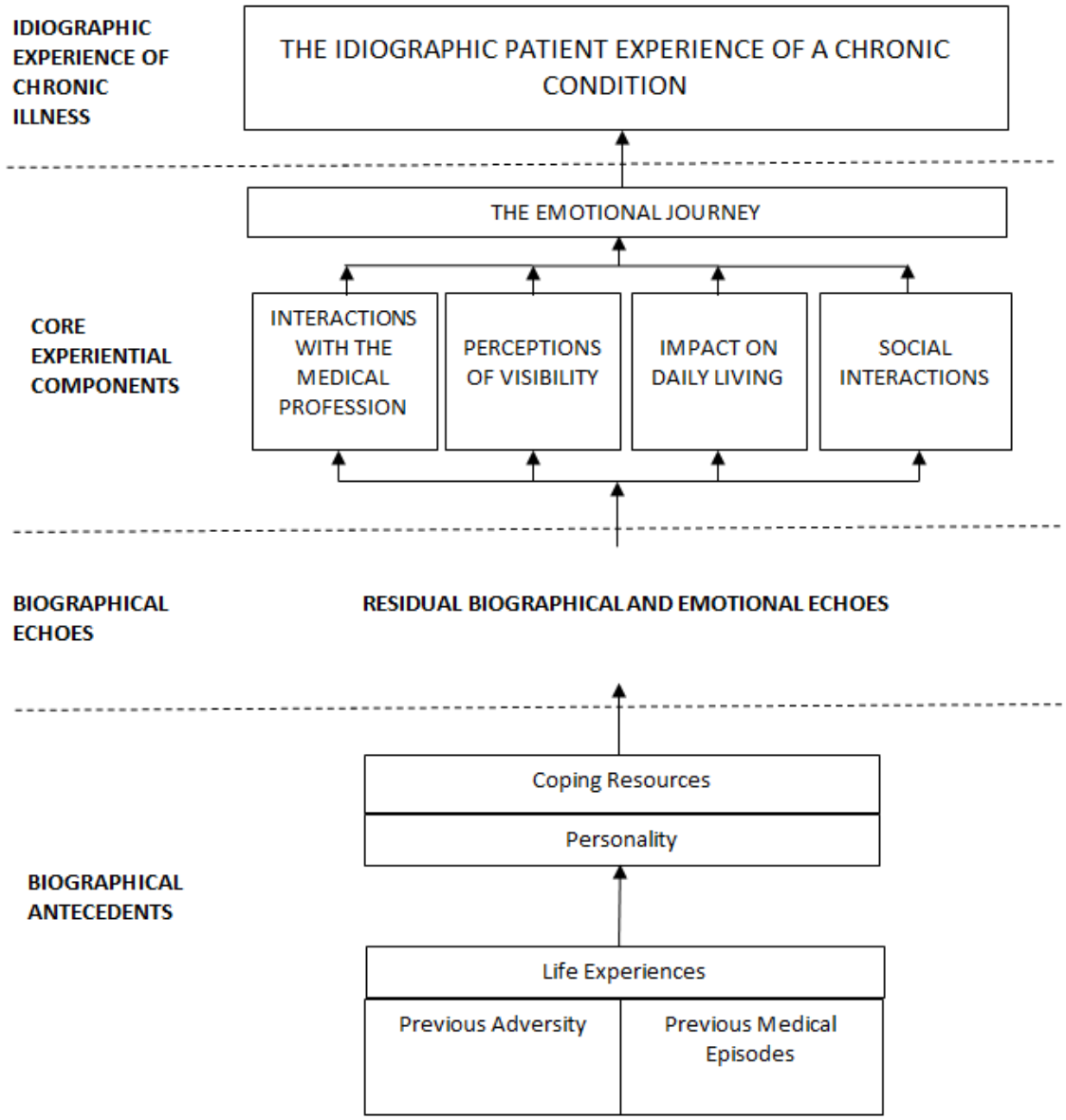


Figure 7: A proposed biographical approach to understanding the idiographic patient experience of a chronic condition.

Biographical antecedents prior to diagnosis have the potential to impact directly on an experience of illness: The broad Life Experiences (ones biography from childhood to the present time) combines with specific episodes of adverse experience and previous medical episodes, to impact on one's personality and the development of coping resources when facing chronic illness. In the way that an audible echo is a reflection of sound that arrives at the listener with a delay after the direct sound

itself, biographical and emotional echoes also arrive at the individual after the initial event and impact on how we experience present events.

Biographical antecedents all impact on future experiences through the residual echoes that once present, permeate the future life course. These echoes can be biographical or emotional in nature and can directly impact upon the four core experiential components those with chronic conditions report experiencing. Each of these elements builds a biographical narrative that impacts on the emotional journey of the individual through their illness experience. Due to the nature of our biographies being unique to ourselves, the idiographic nature of chronic illness experiences is highlighted though this biographical approach.

5k. Implications for Practice

This present research is set within the interpretive paradigm. It is therefore not the aim of this research to produce generalisable conclusions that are applicable to all. Conversely this research journey, through the application of a systematic approach to literature searching and a biographical research method has highlighted that whilst four core experiences transcend each of the chronic conditions, the nature of ones experience of their chronic condition is a result of their previous biography. Acknowledging this, the following question is proposed to start of a conversation led by health care professionals to gain insight into the potential complexities an individual might experience as a result of their diagnosis with a chronic illness.

> *"Does this present experience mirror anything you have felt or experienced previously?"*

The results of this conversation may shed light, to both the individual and their health care team, as to which coping strategies they might be able to action and how the doctor-patient might progress. For example, does the individual wish to be passive or active in their healthcare journey?

Similarly when training health care practitioners it is important to enhance their understanding of humanisation in health care (Todres et al. 2009) by appreciating that each individual will have biographical echoes that are impacting on their present experience of health care. This personal understanding of the idiographic experience will directly serve to minimize the homogenisation present in dehumanized health care practices (Todres et al. 2009) - such as those experiences presented within this thesis.

With the long-term nature of chronic health conditions drawing upon the individual's emotional resources, an understanding of how that individual has coped with previous adversity may support them and their health care team in the individual's journey towards positive living.

CHAPTER 6: CONCLUSION

The purpose of this study was to answer the research question, How have I, a young, active female, experienced living with premenopausal osteoporosis. This research is important in order to start to gain an understanding about the implications of being a non-traditional patient for the condition. This research is the first of its kind, both in exploring the experience of living with premenopausal osteoporosis but also in using a reflective topical autobiographical approach to explore chronic illness. The study differs from previous work in the field of patient experiences of osteoporosis as it not only provides the first in-depth, first-person account of an experience of osteoporosis, it also provides the first account of an experience of premenopausal osteoporosis. Previous studies (albeit limited in number) have explored the experience of the condition for a postmenopausal female, and have included only short quotes from multiple interviews in which no age or background information is available to link specific participants to specific elements of transcribed data. With this method of data presentation, it is hard to truly appreciate the experiences that the participants have lived through. The current study offers a unique (and timely) insight into the experience of living with osteoporosis as a young active female, by a young active female with osteoporosis, through rich description and reflective accounts.

The explicit contribution to knowledge of this research in addition to the account and reflection of the patient experience is the proposal of a conceptual model that acknowledges within it the biographical nature of experience and highlights the role of biographical and emotional echoes. In the way that an audible echo is a reflection of sound that arrives at the listener with a delay after the direct sound itself, biographical and emotional echoes arrive at the individual after the initial event and impact on how we experience present events. Familial narrative maps form a key part of these echoes. With osteoporosis often being genetic, many generations of women will see their own mothers go through the condition, before they themselves reach older age. This viewing of ones future self could either calm or exacerbate the individual's worries over the future presentation of their condition.

The current study found that the experience of living with premenopausal osteoporosis was multidimensional with seven key components: A varied and often negative experience of engagement with the medical profession; the combining of profession and personality type to use information seeking as a coping mechanism resulting in the role of educated patient; how much of a stranger a young woman is to the biomedical world of osteoporosis; the complex relationship with the invisibility of the condition, its periods of visibility through fracture and the intricacies of disclosure; the interplay between the individual and others in terms of social interaction; the impact on the relationship with physical activity; and the resultant turbulent emotional journey.

Firstly engagement with the medical profession was a variable experience due to the range in knowledge presented by different professionals. The general lack of knowledge demonstrated by all professionals below the level of Consultant Specialist, reinforced a feeling of being stranger within the biomedical landscape. Each of these elements drove forward information seeking as means of trying to drive forward my health care to a positive outcome.

The invisibility of the condition had both positive and negative implications. Not knowing how the condition was progressing through its invisibly caused negative feelings of frustration and uncertainty. Invisibility also created an element of 'out of sight out of mind' providing relief from worry and fear. Seeing visible physical reminders of fractures was solely associated with negative emotions and brought the condition to the forefront of ones focus.

Social interactions involved the protection of loved ones from the emotional journey associated with processing the condition as part of one's life and the reactions of support of partners. Engagement with others with the condition caused upset due to seeing frail representations of the condition. The invisibility of the condition presented the factor of deciding when or even if to disclose the presence of the condition to others.

Physical activity was affected in a number of ways. Training with purpose, as opposed to training for enjoyment or stress relief, caused a previous coping strategy to now become a stressor in its own right. Loss of trust in the body created feelings of fear when engaging in previously valued activities such as skating or mountain biking. The overall experience was one of an emotional journey that incorporated fear, uncertainty, and frustration.

The experience of living with the condition did not align with any of the previously proposed models of chronic illness experiences but did align to the biographically orientated stress injury model that incorporates previous life experiences into the nature of the present experience.t

6A. Strengths and Limitations of this Research

The strengths of this research lie in the comprehensive review of literature that highlighted both the gap in literature and the idiographic nature of chronic illness experiences. The approach taken to address the research question developed as the researcher similarly developed in their research journey. What was initially a prescribed approach to an illness experience became an autobiographical study. This development was in response to recognising the biographical nature of the condition and the need to truly embrace methodology to answer a research question, rather than provide an isolated account of the experience with no reference to the impact of the previous biography on that experience. Finally to be able to focus solely on a case of one, has enabled a deep and meaningful account to be produced, that encourages both the imagination or, and subsequent resonance with, the reader.

Each of the aforementioned strengths of the research could also be seen as a limitation, should the reader situate themselves within a different paradigm. The case of one meant that the ability to generalise the findings is limited – although this was not the aim of study. The implications of time and writing of experiences from the past has been acknowledged within Chapter Three, section 3G and is an accepted

part of autobiographical writing. This limitation was negated through the use of diary data that explicitly documented the experience in time.

It is recognised that this research is only one of a number of possible representations of experience that could have been used to achieve the aim of the research. As with all autobiographical work, the present has impacted on the telling of the past (Usher 1999). The writing of the reflective topical autobiography (RTA) took place six years post diagnosis. At this time the RTA method was one that allowed the story to be told, but from the emotional distance of collating and linking diary and blog entries (that is, reorganising data to create a story). This distance was needed in order to emotionally cope with the task of revisiting the experience and to try and maintain emotional control over the process/research. Had the writing taken place from a different 'present', the presentation of the story would perhaps be different and more aligned to the overtly recognisable approach of Lived Life / Told Story (Wengraf 2001).

One consequence of completing the research as an RTA, in which diary entries were used to construct the narrative, was that the story was 'told' rather than 'shown':

> "…the distinction can be taken quite literally: in the showing mode, the narrative evokes in readers the impression that they are shown the events of the story or that they somehow witness them, while in telling mode, the narrative evokes in readers the impression that they are told about the events" (Klauk and Koppe 2014)

The story was told, as that was the mode of presentation that was emotionally possible at the time of writing. If there was a greater emotional distance between me, the writer, and the experience, the ability (willingness) to reconnect with that time in a way that would allow the showing of the story to the reader, would have been possible and would have caused less emotional harm than if it were competed as part of this present study.

In Chapter Three (section 3J) the quality criteria of verisimilitude, evocativeness and enlightenment, were presented as a means of judging this PhD research. The research has presented a plausible account of the experience of living with

premenopausal osteoporosis (thus achieving verisimilitude). This has been achieved through the use of diary entries as the base from which the narrative account was constructed. The story therefore represents the personal truth as it was felt and recorded at that time. The use of a thick description, a narrative based on written experiences collected at the time of the experience, in addition to the raw data (diary) excerpts has created a piece that is evocative in nature. Readers should be able use their imagination to empathise with the experiences within the account. Through providing the first experience of living with osteoporosis as a young premenopausal woman the research is enlightening, both in the story told and in the methodology used – there has been sociological enlightenment through the use of autobiography and its aim using a single case to highlight broader sociological issue (Mills 1959; Denzin 1989) (such as dehumanisation in the healthcare of non-traditional patients for conditions). It has been noted earlier in this section however that were the story to be written in a different present, by showing the reader the experience, the story may have been more evocative and thus more enlightening to readers on a personal level.

6B. Dissemination of Findings and Progression of the Research

As this research draws to a close a reflection on the experiences so far of both presenting and defending the research is offered. The research findings have been presented in a number of forums (listed later in this section). Each subsequent presentation has developed from initially talking emotionally about the experience, to a researcher led discussion about the research project and its findings…The defence of this thesis in the viva voce however, was in stark contrast to this un-emotive reporting.

Once Chapter Four Part Once was written and 'signed off' by my supervisors, that story was never reread…I knew the story, I had lived the story and I was all too aware of the ending. Rereading and revisiting that story would not change the biomedical outcome for me. The story became the data for interpretation, a process

by which I could mentally remove myself from the story itself and become more analytical.

Whilst sitting in the viva voce I was reminded, through the comments and questioning, that the story was in fact MY story. That the events we were discussing were deeply connected to emotional reactions held deep within me…The experience of the viva voce was one in which I reconnected with those emotions (that I had distanced myself from through data analysis but was now confronting) in front of an examining team. The result of this viva voce was a strong desire by me to embargo my story, to finally move on from that emotional time in my life and bury it in my biographical past. This desire came from both a need to maintain control of the story not yet feeling ready to send it out to the ether for others, combined with a concern over my story becoming my researcher identity.

Prior to this defence experience it was hoped that the initial progression from the completion of this thesis would be in the form of identifying others with low bone density and exploring both an autoethnographic study and one that looks at the biographical echoes model in relation to the participants' experiences of their condition. These research themes could similarly be broadened and used to understand the experiences of those who are classified as non-traditional patients for their conditions. As it stands at present I feel I need to step back from the emotions of myself and others and work to use the findings in a biomedical sphere initially, to educate practitioners on the key biomedical findings of this work, for example, the correct indicators and criteria to be used for the diagnosis of osteoporosis. Over time, as I can loosen the control of my story through the benefit of emotional distance, I hope to show others the experience in order that the initial intent of evocativeness and enlightenment can be truly achieved.

This research has however ignited a desire to continue to explore the experiences of women who feel they sit as strangers in their demographic groups, for example those with early menopause. It is my intent that through the provision of demographically specific stories, women can support each other through

biographically disruptive conditions and provide new desired self-narratives for their progression through the life-course.

The dissemination of the findings of this research, and the research process, has started in a number of ways as outlined below:

Conferences

Thurston, J. 2017. 'My Bones Won't Break Me:' My experience of living with osteoporosis as a young, active female. *Humanising Care, Health and Wellbeing Conference,* Bournemouth 29 Jun 2017.

Thurston, J. 2017. Improving primary care provision through understanding the experiences of strangers within diagnostic groups. *Primary Care Workforce Conference.* Bournemouth 22 November 2017.

Thurston, J. 2017. Transitioning one's private experience into the public domain. *British Sociological Association Auto/Biographical Study Group Christmas Conference – Private and Public Lives.* London 8 December 2017.

Thurston, J. 2018. Proposing a 'Biographical Echoes' approach to understanding the ideographic nature of patient experiences and promote humanised health care practices. *Humanising Care, Health and Wellbeing Conference,* Bournemouth 21 Jun 2018.

Thurston, J. 2018. 'Observing my Future Self': Understanding the impact of ageing family members on one's own anticipated progression through the ageing process. *British Sociological Association Auto/Biographical Study Group Summer Conference – Auto/Biography and the Family.* Oxford 19-21 July 2018.

Journal Papers

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., Podee, M., (2018). From 'I' to 'We': A Collaborative Study Group Approach to Narrative Research. *The Qualitative Report*. *Under Review*

EPILOGUE: Writing for Researcher-as-Participant Research

> "Reflection is a critical part of learning from experience and is important in developing and maintaining competency…" (Paterson and Chapman 2013, p.133).

I am a practitioner of musculoskeletal sports injury management, pedagogy and research. Reflection is a requirement for each of these roles. This PhD thesis ends, perhaps unexpectedly with an Epilogue documenting my reflections on the completion of this research study using a researcher-as-participant methodology. Whilst structured models of reflection are published (see Gibbs 1988 and Kolb 1984, for commonly used examples) the writing of this thesis was part of the experience of living with the condition documented in this thesis. The two are inseparable. With the diagnosis in April 2011, doctoral work started in August 2011. This has resulted in the decision to provide a final reflection in a similar format to others in this thesis. Once more, the aim is that the reader may imagine and resonate with the account that follows.

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 (Baron 2009). Health care professionals report that hearing these accounts have in impact on both their professional and personal selves along with increased empathy and a deeper understanding of the lived experiences (Bragazzi 2013). Patients themselves have reported that through being able to tell their story of their lives and illness journey, they felt a sense of "release" (Towle 2014, p.305) and were able to seek meaning and gain healing (Candib 2004). Health care professionals find the layers of awareness that a patient experience evoke have a far greater impact on them than the same information gathered and presented in more traditional means such as report, statistics or patient experience survey (Baron 2009). Increased use of the life-world in medicine makes for better outcomes and more humane treatment of patients as unique human beings (Barry et al. 2001).

But to be the researcher who is now exposing their private world in order to add to wider understanding the process has been particularly and unexpectedly difficult. Publically I am an academic within a university and programme leader for a new degree for which I wrote the curriculum and steered through validation. I have a ten-year professional career before moving to higher education in which I was a sports injury rehabilitator for athletes from community up to international level. Until 2011 my only understanding of osteoporosis was from my textbooks and training for my sports injury profession.

One moment changed everything for me: The moment when the doctor asked me "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 a process which now, seven years later I hope to (and need to) draw to a close. The information seeking, that my response to that question started, was initially from the perspective of a patient. A scared, overwhelmed patient desperately needing to find a way out of her present situation. Yet I found that as an educated patient – someone trained in musculoskeletal health, with access to university level search strategies and databases – the more I read, the more I processed the information I was reading from my professional perspective. Everything I read was biomedical in nature at this point. I needed to learn about the condition and learn how to 'fix' it. Any glance at patient stories etc, would leave me fighting to control tears and panic. As the weeks rolled by, 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.

I should never, according to the literature have been given a diagnosis of osteoporosis (just low bone density); I should never have been offered bisphosphonates (as I was of child bearing age); by the age of 20 years old I had presented to my GP with a total of five independent risk factors for osteoporosis (very low body fat, low body mass index, late onset of menses, anxiety and depression, selective serotonin reuptake inhibitor medication) yet bone health was never mentioned to me by health care professionals.

The process of choosing and writing a PhD within a research area that is 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. To be able to express myself in a written form somehow eased the pain (temporarily) that a situation was causing me:

> "I am sat at work having a cry! I am writing my PhD proposal and so reading about 'disrupted life-courses' when diagnosed with a chronic disorder, 'disrupted identities' of people who once saw themselves as fit and healthy but are now labeled as not being so, and learning how to write a reflective account of my experiences by reading the experiences of others after a diagnosis……..So I found myself with my head in my hands at my desk having a good cry about my bones (for only the 3rd time since diagnosis). I keep forgetting that whilst I am excited about writing my research and doctor trips/ shopping with Mum in London are great fun…This is actually happening to me…I have osteoporosis and I just don't want it."
>
> (12/07/2011 – Blog Post – Three months post diagnosis)

The nature of choosing a researcher-as-participant methodology, however, meant that whilst I wrote (because that was my way of coping with any negative situation and had been since I started my diary at age 14 during the bullying at school), there came a point in my recovery where the commitment to the PhD conflicted directly with my desire to move forward from the upset and try to minimise my concerns over the potential future my condition may have brought:

> "I think I have chosen the worst PhD topic ever. I just don't get what I am supposed to be doing. I know I am supposed to be gather data, writing diary entries etc etc but I don't want to think about my bloody bones any more than I have to."
>
> (05/10/2011 - Diary Entry – Six months post diagnosis).

The period of time six months post diagnosis corresponded with being three months into my PhD journey … and more importantly the start of the new academic year. As a first year level tutor, unit lead for two large cohort units and lead academic for employability and CPD for our students the continued writing and reflection on my condition and emotional state conflicted with the demands of the business. I found

this period particularly difficult as represented by the following diary extract from that first week of the academic term:

> "If I don't think write or talk about it then as far as I'm concerned it isn't happening. So having to write stuff down goes against my coping mechanism I've developed over 20+ years! It would be wrong of me to give an impression of detailing my journey each day because that is not me. I might think about it daily but by writing it down it's a deceitful way of presenting my coping mechanisms."
>
> (05/10/2011 - Diary Entry – Six months post diagnosis)

Even ten months post diagnosis I still had periods where the process of the data collection necessary for the PhD – despite happening anyway with my diary writing – was only a negative as far as I was concerned. I had reached a point of acceptance over the condition, albeit with a strong element of refusing to accept that I would not increase my bone density through training, and I resented being brought back to thinking about potential outcomes if that was not possible. I still found the reading of other people's experiences particularly difficult even at this point after the diagnosis.

With the pressures of the second semester building in March (11 months post diagnosis) I once again found the incorporation of my chosen methodology with my role as a teaching academic particularly difficult. I had a busy timetable spread out across the working week and being a part time PhD student I 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:

> "Health autoethnography over any period of time is hideous. I cannot remember feeling this overwhelmed and stressed in years. The nausea of stress is getting to a point where on some days I cannot function. I know I need to write but sometimes what I want to write down clashes with work and I can't cope with pouring my heart out in here and then thinking 'Right, on to Level C Biomechanics!"
>
> (07/03/2012 – Diary Entry – 11 months post diagnosis)

Having a second DEXA scan one-year post diagnosis and seeing that my bone density had improved markedly due to my weight training, I had a summer of elation, no teaching and finally a mental break from the stress and anxiety that had haunted me. Feeling reinvigorated I threw myself into my PhD yet still only focused on the biomedical aspects and wrote numerous sections based solely on medical research. I can now look back at those sections (all unused in this final thesis!) and see a patient still desperately looking for answers, trying to rationalise the presentation of bone health from a biomedical perspective. Yet the process of writing and reflecting, even on positive events such as the increase in bone density, always led me back to thinking of the future and the uncertainty that would bring:

> "I haven't had to think about my bones really in ages, apart from when on my bike and out of sight out of mind is working brilliantly for me! My general level of panic has dropped so much since I found out my bones have improved a bit but now as I write this I'm forced to face the reality that they haven't improved LOADS and I'm still osteopenic and will still end up osteoporotic post menopause – God health autoethnography is so disgusting – It makes you face reality which just makes everything so painful. This PhD was a dumb idea!"
>
> (13/09/2012 – Diary Entry – 1 year 5 months post diagnosis)

By this point in my journey post diagnosis, I was writing less in my diary and feeling as if I was coping with the situation that I was in. Writing for me had always been reserved for negative emotional situations and was a chore if I was actually feeling happy!

> "I feel AMAZING! I want to tell the world! The relief is overwhelming and strangely it is an effort to sit down and write about it (this has been sitting in my 'drafts' since 2nd July when I got the news!!!)"
>
> (02/08/2012 – Blog Post – 18 months post diagnosis)

The silences in my diary, the happy weeks where I didn't write anything were wholly reflective of my emotional state. I was no longer despairing. Anything that I did write in my diary or on my blog was now less to do with my own state of mind and feelings of despair and more concerned with my reaction to research that I had read.

> "I try and write a bit of my PhD each day and usually manage to keep my unemotional 'researcher' head on as I read the literature on the subject.

> Today however I read something which unleashed the 'patient' within me and has left me feeling completely overwhelmed at the task ahead of me. Morris et al (2004) completed a systematic review of the literature looking at the formulation of clinical guidelines for sending patients for BMD testing. Between 1992 and 2002 of all the papers looking at clinical guidelines none…zero….NO guidelines included a premenopausal female with risk factors."
>
> (29/10/2012 – Blog Post – 18 months post diagnosis)

In January 2013, I only wrote two diary entries: One was over my excitement that it had actually snowed quite considerably in my hometown, so university was closed! This led to my resenting the fact I was choosing shoes by their tread depth but the rest of the entry was about the day out that my new boyfriend and I had had, stomping through woods and eating pub food and how cared for I felt with this man…He held on to me for the entire day to make sure I didn't slip! The next day I wrote about a fear of slipping in the university car park as I was in trainers (to teach a practical session) but again that was superseding by my happiness at having met Tony. He had read my diary and blog, still wanted to be with me and now had my BUPA number in case I broke anything and needed admitting to hospital!

Beyond this point, my PhD journey varied its course on a number of occasions. Tony proposed in June 2013 and so planning a wedding and completing my PGCertHE became priorities over reflecting on my potential future. In October 2013 my mother received a cancer diagnosis and I suspended my studies for the period of her [successful] chemotherapy in order to take over her role as carer for my grandmother. Tony and I got married in May 2014 having carefully negotiated the date with my mother to give her something to look forward to at the end of her treatment, and one month later, I started to feel nauseous! Our daughter arrived in March 2015 following which I suspended my studies once more for my nine-month period of maternity leave.

My return to work in December 2015 was a turning point in this research. I was asked to move Faculty from the Faculty of Management (where the Sports Degrees were housed) to the Faculty of Health, where I was asked to write and lead the new BSc (Hons) Sports Therapy programme. This move prompted a change in my

supervisory team to my current team and it is this combination of changes that led to the biggest progress in this research.

In the Faculty of Management a first person methodology was automatically termed autoethnography (hence my referral to health autoethnography in my diary entries). Within the Faculty of Health there were numerous senior colleagues using a multitude of qualitative methods and instead of fearing a PhD research study with a sample of one (unheard of in my previous faculty) and I started to progress my understanding of methods to embrace the depth that this research could offer and its unique contribution to the academic community.

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 autobiographical 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 wanted to 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 autobiographical work and been involved in a biographical study group (see Cooper, Oliver, Podee and Thurston 2017), I could finally admit that I knew why I had osteoporosis. I tried as hard as possible to ring fence this chronic illness experience from the rest of my life and treat it as a distinct point in time. But, in knowing why I had osteoporosis, I was acknowledging that my past was affecting my present, and to provide a true and accurate account of my experiences I needed to acknowledge that within my methodological choice.

The implications of choosing an autobiographical method were multidimensional. Issues of identification and protection of loved ones was a major consideration as familial terms like mother and sister automatically identify others within my story. My ex-boyfriend was not someone I wanted to visit to gain consent for inclusion in the study, and as such, I have ensured that he is completely unidentifiable to anyone that did not have a knowledge of us as a couple at that time.

The biggest implication for me, however, has been one of control and disclosure. If you google my maiden name, the Internet presents you with newspaper stories of me having bones as "old as my grandmother's", photographs of my meeting with patrons for the National Osteoporosis Society and other work I did to publicise premenopausal osteoporosis as I started my research into the condition.

Whilst changing my name as a result 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 this 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 et al. 2014). Similarly, Olshansky et al. (2008) reported that those with diabetes were trying to move their self-identity to that of a person with diabetes rather than being 'a diabetic'.

I now have a daughter, and whilst I am sure open and honest conversations will happen between us over the years she will be able to, if she wishes, read about my most upsetting of times. Similarly, my parents could read about a time from which I have worked so hard to protect them. Finally, I am an academic within the competitive world of Higher Education. When I first mentioned I was completing an 'autoethnography' 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.

As I reach the end of this process, I feel confident in the fact the skills I have learnt during this process have been enhanced by the fact that this research is on myself, rather than feeling limited by it. Committing to a research project that makes the

most traditionally arduous of elements (such as the literature review!) a painful reminder of one's potential future, has armed me both as a research and as an individual, with a resolve of which I am most proud. This PhD was more than an academic research exercise. It was my life for five years.

I am however a little nervous to finish this research. It has been a focus in my journey over the last five years, and I am nervous that once completed I lose that focus and become just a person with osteoporosis. A person who still has no idea what her future holds, who is still fearful of spinal fractures and who never wants to become a burden to anyone. Whilst it is hoped that this thesis and the resultant publications help those who find themselves in a similar situation, a further hope is that practitioners are encouraged to understand the deep multidimensional implications of a diagnosis of osteoporosis for a young women. For me the finishing of this PhD marks the end of a coping mechanism. Ironically, it is also the completion of this PhD research that has taken me away from the one intervention that I knew had worked to help build my bone density…Weight training. In fact, since having my daughter three years ago, I have been unable to find the time to go to the gym at all and so the time has come to leave this thesis and return to trying to maximise my own future bone health. My ultimate hope is that the dissemination of my experience supports others who find themselves either a biomedical stranger, have been diagnosed with premenopausal osteoporosis, is training within the health care profession, or is contemplating a researcher-as-participant study for their doctoral 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).

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APPENDIX A – Ethical Approval

Bournemouth University

Research Ethics Checklist

Reference Id	2157
Status	Approved
Date Approved	24/02/2014

Researcher Details

Name	Joanna Hawkes
School	School of Tourism
Status	Postgraduate Research (MRes, MPhil, PhD, DProf, DEng)
Course	Postgraduate Research
Have you received external funding to support this research project?	No

Project Details

Title	'My Bones Won't Break Me': An auto-ethnographical exploration of premenopausal osteoporosis in a physically active female.
Proposed Start Date of Data Collection	01/11/2013
Proposed End Date of Project	01/11/2016
Supervisor	Sean Beer
Approver	Sean Beer

Summary - no more than 500 words (including detail on background methodology, sample, outcomes, etc.)

With 200 million people worldwide having osteoporosis in 2006 (Reginster and Burlet 2006) the literature to date has predominantly focused on the most common and traditionally accepted presentation of the disorder, primary osteoporosis. This is the accelerated natural decline of bone density related to ageing and the subsequent lack of oestrogen in the post menopausal female (Gold et al 1991). There are however two further forms of the disorder: secondary osteoporosis, being bone loss from specific well defined clinial disorders (Fitzpatrick 2002) and idiopathic osteoporosis where healthy premenopausal women have very low bone density and a resultant high risk of fracture (Liu et al 2010). Literature surrounding these lesser documented conditions focus on clinical signs and data sets, with minimal reference to the lived experience of diagnosis for the patient.The diagnosis of osteoporosis for a premenopausal female may present particular challenges, such as disrupted identity (Karnilowicz 2011) and life course expectations (Exley and Letherby 2001). Numerous papers discuss the experiences of patients diagnosed with chronic conditions, yet the premenopausal osteoporotic female patient; their experiences, rationalisation of their life course and exposure to potential causative risk factors is noticeably absent from the literature. Exploring humanisation in healthcare has been highlighted as a priority to build practitoner knowledge and develop practices. For those patients who find themselves atypical for a condition, such as a premenopausal female diagnosed with osteoporosis, it is even more important to explore their experiences of healthcare, as the mechanisms to which they are exposed (investigation, medication, support groups etc) are established for the traditional patient demographic (post menopausal females). The premenopausal patient may as a result find that they occupy the position of 'stranger' not only within their experiences of healthcare provision and their social peer group (as their diagnosis places them outside the boundaries of those around them, Exley & Letherby 2001) but also a stranger within their diagnostic group due to their unique demographic. 'Health autoethnography' has developed in the last 10 years, to provide a voice to those diagnosed with chronic conditions (Ettorre 2010) and so provides a platform from which to explore humanisation in healthcare. The expert on the 'lived experience' is not the researcher but the patient (Richards 2008). I am an active, premenopausal 33 year old, with a history in physical activity and sport, who, has been diagnosed with osteoporosis with no specifically identifiable single 'medical' cause. As such I consider myself a 'non-traditional' patient (Exley & Letherby 2011) for this condition and in a unique position to employ analytic autoethnography (Anderson 2006) to explore not only my experiences but also to examine the physical, social and psychological risk factors and the subsequent processes in which I have engaged. In writing about chronic illness and disease, the literature is often authored by 'outsiders,' such as doctors and academics and the patient's (insider) 'expertise is occluded' (Richards 2008 p1717). Many have written about the extent to which any researcher or author can be an 'expert' about the experience of another person (Foster et al. 2005). These authors 'cannot but represent their experiences through their own professional lenses, however much they might try to do otherwise' (Kirmayer 1992 cited Richards 2008). In response to this health autoethnography has developed and become more visible within the chronic illness literature. Ultimately it can be argued that the true expert on the patient's experience of living with illness is not the medical professional or academic researchers but the person experiencing the illness (Richards 2008). Autoethnography through the use of blog posts and diary entries will be employed within this research to provide a first hand patient narrative for thematic analysis to which coding and categorisation will be used as the basis of exploration and analysis, true to the qualitiative agenda for healthcare.

External Ethics Review

Does your research require external review through the NHS National Research Ethics Service (NRES) or through another external Ethics Committee?	No

Research Literature

Is your research solely literature based?	No

Human Participants

Will your research project involve interaction with human participants as primary sources of data (e.g. interview, observation, original survey)?	No

Final Review

Will you have access to personal data that allows you to identify individuals OR access to confidential corporate or company data (that is not covered by confidentiality terms within an agreement or by a separate confidentiality agreement)?	No
Will your research involve experimentation on any of the following: animals, animal tissue, genetically modified organisms?	No
Will your research take place outside the UK (including any and all stages of research: collection, storage, analysis, etc.)?	No

Please use the below text box to highlight any other ethical concerns or risks that may arise during your research that have not been covered in this form.
The ethics associated with autoethnographical research have been discussed within the literature (Tolich 2010) and this PhD will pay particular attention to the ethical issues autoethnography raises, such as maintaining anonymity of 'unwitting' participants - whether that be through retrospective informed consent or the utilisation of pseudonyms. The combination of the two will be utilised, as ultimately with autoethnographical pieces, once the name of the author is known the immediate family and colleagues can also be identified (hence the need for retrospective informed consent) however doctors and friends for example can be identified using pseudonyms. Throughout the final PhD the method of ethical consideration will be identified where appropriate. There must also be consideration for the effect of the autoethnography on the researcher and as such mechanisms such as a strong supervisory relationship and acknowledgement of support systems in place to work with the researcher are in place should the research be deemed to be having an impact on the researcher throughout the course of the PhD.

APPENDIX B – Consent Form

‘My Bones Won’t Break Me’

A reflective topical autobiography exploring the experience of living with premenopausal osteoporosis.

The above research project is exploring my journey through my diagnosis with osteoporosis. As a family member or loved one you may be identifiable within some of the data extracts (diary entries, blog posts and my personal narrative) presented within the final thesis, through your relationship to me through the use of terms such as ‘brother’, ‘mother’ etc. Please could you sign this consent form if you are happy for this relationship and your familial identification to be included within the PhD thesis? Names will be changed however familial positioning will remain a potential identifying feature unless you express concern over this and are not happy to sign this consent form. You may change your mind at any stage throughout the PhD process up until December 2017 when the final thesis will be compiled ready for submission.

Many thanks

Joanna Thurston

Name:…….

Date:……

Signature:……..