

Original Research

Women's Perceptions of the Embodied Experience of Osteoporosis across the Lifecourse

Alyson Holland ^{1,*}, Amanda Lorbergs ²

1. Michael G, Degroote School of Medicine, Department of Family Medicine, Hamilton, ON, L8S 4L8, Canada; E-Mail: jaagumae@mcmaster.ca
2. Canadian Frailty, Kingston, Toronto, Canada; E-Mail: amanda@cfn.nce.ca

* **Correspondence:** Alyson Holland; E-Mail: jaagumae@mcmaster.ca

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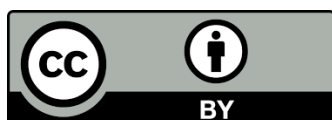
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Abstract

Beliefs about the daily experience of a disease are used to identify risk and motivate participation in prevention. For osteoporosis, a disease that is affected by health behaviours throughout the lifecourse, individual perceptions of the disease can affect health decisions and future disease prevalence. Understanding how the experience of osteoporosis is perceived by women at different stages of life can illuminate factors that influence engagement in prevention. Women representing three life stages - young adults, at-risk older adults, and women with osteoporosis - participated in interviews and focus groups regarding their beliefs about osteoporosis. The young and at-risk adults revealed similar constructions of the osteoporosis experience, however, all three groups viewed osteoporosis as fracture-and age-centric, which served to normalise the disease. For young and at-risk adults, the impact of osteoporosis on daily life was minimized and susceptibility was reduced, leading to diminished perceptions of risk and decreased interest in prevention activities.



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Keywords

Osteoporosis; lifecourse; embodied experience; prevention

1. Introduction

Osteoporosis is the most common metabolic bone disease in Canada, affecting approximately two million Canadians [1]. Defined as a disease of bone degeneration, osteoporosis occurs when a greater percentage of bone is removed than is formed during bone turnover. As a result, osteoporosis is considered a disease of low bone mass, microarchitectural change, and increased fracture risk. Bone density is lost over time, leading to thinner, weaker bones that are prone to fracture [2]. Fractures are considered the defining feature of osteoporosis and avoiding fracture is the focus of prevention initiatives and treatment regimes. Osteoporotic fractures affect 2 million Canadians and carry an economic cost of \$2.3 billion, a number that is expected to steadily increase with an aging population that is living longer [1]. Osteoporosis appears most commonly in the later decades of life, since this is when degenerative processes related to senescence lead to an uncoupling of the formation-resorption cycle of bone. The rising incidence of osteoporosis combined with the increasing expense of treatment has led to a focus on creating and implementing guidelines for osteoporosis prevention and management [3, 4]. Since bone degeneration can be treated, but not cured, osteoporosis represents a chronic health condition that can have significant ramifications to the Canadian population.

This paper is an exploratory study of how the experience of osteoporosis is perceived by women. A lifecourse framework drawing upon the Health Belief Model (HBM) is used to explore the relationship between perceptions of embodied experience, risk, and health behaviours. Decisions about prevention are influenced by individual beliefs about a particular disease experience; therefore, understanding how a disease is conceptualised throughout the lifecourse is important for predicting engagement in prevention and development of osteoporosis throughout life.

1.1 Osteoporosis and the Embodied Experience of Disease

The majority of osteoporosis research is aimed toward identifying disease etiology, management options, pharmacological agents, and prevention initiatives [4-10]. The dominance of these approaches in the literature results in a biomedical focus for osteoporosis research. While this knowledge is essential for treatment of the biological changes associated with osteoporosis, it results in the discourse surrounding osteoporosis becoming fracture-centered and isolates fractures as the most significant aspect of osteoporosis. Similarly, prevention information focuses heavily on diet and exercise, as these are viewed as modifiable changes, though it is recognized that osteoporosis risk is determined by a wide variety of factors including genetics, weight, smoking, and alcohol intake.

Defining a chronic disease around a single symptom excludes the psychosocial effects of the daily lived experience of having a condition that is permanent and debilitating. Lived or embodied experience is an important aspect of chronic disease often overshadowed by medical research

because it is intangible and variable, making effective quantification or management difficult [11-13]. The need to consider the embodied experiences of disease lies in the relationship between daily lived experience, psychosocial effects of chronic disease, and beliefs about risk. Instead of looking at the biological disease, it is necessary to consider the illness – the socially constructed meaning of having a particular disease – which goes beyond the physical manifestations of that disease, such as fractures [14, 15]. Osteoporosis is associated with depression, stigma, altered perceptions of self and the body, fear, anger, isolation, dependence, and vulnerability as a result of the potential or existing physical changes [16]. When disease is located within the fracture event these pre-existing and lasting effects are not considered in the patient's experience and as a result are not integrated into prevention or treatment plans. This is problematic because these experiences must be managed on a daily basis and can manifest before a fracture occurs or continue long after a fracture has healed.

There is a large body of work on osteoporosis, reflecting the importance of and interest in the topic. However, the number of articles that focus on disease experience represent a small fraction of osteoporosis research. Hoang-Kim et al. [11] conducted a search using the SCOPUS database and found only 48 articles that discussed the experience of osteoporosis. Though osteoporosis is rarely written about in the social sciences there are select authors who regularly discuss issues related to embodiment [16-18]. Only one ethnographic description of osteoporosis has been written, which details an individual's difficulty with recovering from vertebral fractures, including the loss of independence, pain, and fear associated with fracture and chronic disease [19]. While there has been an increase in social epidemiological research into the factors that affect osteoporosis risk and prevention, such as socioeconomic status and health literacy [20-22], qualitative descriptions of lived experience are uncommon.

Since the majority of osteoporosis research is fracture-centered, the framework used by public health organizations focuses on fractures [3, 4, 8]. Osteoporosis Canada, a non-governmental organization that focuses on osteoporosis, is attempting to bridge this gap by emphasizing the loss of independence and deformity associated with the disease in order to encourage prevention behaviours; however, this discussion represents only a small portion of their education. A narrow focus on physical problems is concerning because public health information is designed to aid individuals in recognizing and mediating their own risk. People evaluate risk and make decisions about their health based on the perceived severity and significance of a disease, an idea outlined in the Health Belief Model [23]. By excluding the lived experience from the discussion of disease, it becomes difficult for an individual to properly evaluate disease seriousness.

1.2 Adopting a Lifecourse Framework

Bone growth is greatest during childhood and adolescence, with longitudinal growth completed by the late teens to early twenties [24]. Bone continues to grow appositionally until the mid-to-late twenties, when peak bone mass is attained [25]. After this point all bone growth ceases and maintenance begins, leading to an overall decrease in bone mass and density over time. While bone mass and density decrease naturally, deficiencies in diet and lack of exercise can increase the amount of bone lost [26]. This means that rather than being a degenerative process that begins in the later decades of life, development of osteoporosis is actually influenced by behaviours throughout a person's entire lifetime.

Actions throughout life can affect osteoporosis risk; therefore, a lifecourse framework is a useful tool to investigate the disease. The lifecourse approach involves examining the development of osteoporosis within the context of the individual's entire life, rather than an isolated event associated with later life [27, 28]. In this context disease is recognised as the result of many events, either a disruption at critical periods in life or a chain of events that eventually led to disease. As a result, perceptions of osteoporosis risk are likely to change throughout the lifetime, which will affect interest in engaging in prevention. Previous work by Backett-Miburn et al.[27] investigated changing perceptions of osteoporosis over a ten-year period in middle-aged women, but did not include women from other life stages, such as younger women or those with osteoporosis.

1.3 The Health Belief Model

The Health Belief Model serves as an important guide for understanding the relationship between risk and decision-making and works well when partnered with a lifecourse framework. A person's assessment of their risk of a particular condition informs their decisions about engaging in prevention behaviours, such as changes to diet or exercise patterns in relation to osteoporosis [23]. The perceived severity and susceptibility to a disease influence perceptions of risk, so the greater the severity of the disease and the more susceptible a person believes themselves to be, the higher the risk level assigned to the disease by that person [23, 29]. Additionally, the fewer barriers a person sees to prevention and the greater the benefit associated with prevention activities, the more likely a person is to engage in prevention activities, such as changing diet or exercise patterns. When combined within a lifecourse framework it becomes clear that the decisions people make at different stages in their lives are associated with these individual perceptions of disease. How a person negotiates their decision-making in relation to their health is a product of their beliefs about the future experience of a particular condition. If osteoporosis is seen as a severe condition that will affect life negatively and the individual feels they have a high susceptibility, then they are more likely to make decisions that minimize their future risk [10, 29]. Individual beliefs regarding the experience of disease are therefore extremely important in determining perceived risk and could affect future disease incidence. Applying the HBM within a lifecourse framework allows for the investigation of the connections between experience, risk perception, and prevention. The lifecourse framework incorporates the multi-vocal views of risk occurring at different life stages, while the HBM guides the exploration of how experience can be translated into prevention decisions.

2. Methods

In order to capture beliefs about osteoporosis at different stages of life three groups of women representing specific age and risk categories were selected: young adults, older at-risk adults, and older adults with diagnosed osteoporosis. Ethics clearance was granted by the McMaster Research Ethics Board and the Hamilton Health Sciences Research Ethics Board. Only women were interviewed in this exploratory study because osteoporosis affects women twice as often as men and so knowledge and concern about osteoporosis is likely to be higher in women [1]. Eight young adults, defined as being within 17-30 years old, were recruited from McMaster University in Hamilton, Ontario as part of a doctoral research project on osteoporosis and nutrition knowledge.

The age range of 17-30 was chosen because this represents the time period where most longitudinal growth has been completed and peak bone mass is being attained. Due to this, the decisions young adults are making about their diet and exercise can affect development of peak bone mass and future osteoporosis risk. Participants were recruited using posters placed around the university campus, leading to recruitment of a diverse group of young adults reflecting multiple disciplines and educational backgrounds. None had previously studied osteoporosis or had a stated interest in bone health or nutrition.

Nine older at-risk adults were recruited from a recreation center near Hamilton, Ontario. All were members of a retirees club, where they participated in a variety of activities that ranged from playing bridge weekly to being on a volleyball team. Recruitment was done through the use of posters placed around the facility. None of the women in this group reported any fragility fractures, though one had a previous traumatic lower leg fracture. The women were aged 54-82 years and are considered to be at risk of osteoporosis based on their age (women over 50 are considered at risk), postmenopausal status, and sex. Due to the changes in estrogen associated with menopause and the increased degenerative changes to bone that occur at older ages these women represent a life stage that is targeted by physicians and health media to raise awareness of osteoporosis prevention. As a result, awareness of osteoporosis and the importance of prevention is generally higher at this life stage.

Nine older adults who had been diagnosed with osteoporosis were recruited from a Hamilton YWCA Bones Plus exercise class associated with Osteoporosis Canada. These women represented Canadian women living with osteoporosis. Women were recruited at monthly Osteoporosis Canada meetings to participate in a focus group held at the YMCA. While all women had a diagnosis of osteoporosis, we recognize the possible limitation of using women who are participating in an exercise group for bone health. However, their responses are broadly consistent with the literature. The women were between 61 and 84 years and had been living with osteoporosis for a median of ten years. The women had various degrees of degenerative changes; three women reported previous compression fractures. The women had been diagnosed with osteoporosis based on bone density T-scores (considered the gold standard in diagnosing osteoporosis by using standardised measurements of bone density) and all had been receiving pharmacological treatment. While similar in age to the at-risk women, these women experienced osteoporosis on a daily basis, which magnified the role of osteoporosis in their lives.

A combination of focus groups and individual interviews were used to explore women's perceptions regarding the experience of osteoporosis. Young adults were interviewed individually as part of the methodology in the larger doctoral research project, while both groups of older women participated in focus groups to facilitate scheduling and because the women were uncomfortable being interviewed individually. The individual interviews lasted 45-60 minutes, with the portion that focussed on the experience of osteoporosis being between 15-20 minutes. Interviews were conducted in a private room on campus at McMaster University and written consent was obtained from all participants prior to the start of the interview. The focus groups with the at-risk and osteoporotic women lasted 45-60 minutes and were conducted at the recreational center and the YWCA respectively. They were facilitated by one author with a note-taker present and written consent was obtained before commencement of the focus groups. Both the interviews and focus groups used a series of predetermined, open-ended questions that were varied in order to reflect the differential experiences of the group members. For example, the

young adults and at-risk adults were asked what they thought it would be like to have osteoporosis, whereas the women with osteoporosis were asked about their experiences of having osteoporosis. All interviews and focus groups were audiotaped and transcribed.

All interviews were analysed using NVIVO 10 following the process of qualitative content analysis outlined by Graneheim and Lundman [30]. This method of thematic analysis involves the identification of salient themes within the interviews through a process of assigning codes to specific phenomena, objects, or events that represent their interpreted meaning. These codes are then grouped into categories and further into larger themes in order to understand how specific meanings fit into larger conceptual ideas.

3. Results

Two major themes emerged from the data that were consistent across all three groups: fractures and aging. The discussion of these themes and the meanings attached to them varied depending on the life stage. The additional sub-themes identified reflect the differing conceptualizations of the osteoporosis experience generated through the lived experiences of the participants.

3.1 Young Adults

3.1.1 Theme #1 Fractures

"I guess I can't think of any immediate health risks in having degenerated bones other than like a broken bone" (YA03).

Young adults described osteoporosis as a disease where bones break, leading them to view the disease as fracture-centered. Their discussions of osteoporosis focussed on the physical changes that were associated with fractures, including mobility, weakness, and overall impediments to daily activities. Changes to mobility were expressed as the most significant issues associated with the experience of osteoporosis. Young adults felt that osteoporosis could restrict mobility in two ways, either through the fractures themselves or through the loss of strength in bones. Fractures were seen as limitations to mobility that would be frustrating, uncomfortable (in the case of pain), and possibly lead to a loss of independence through the inability care for themselves, but would resolve when the fracture healed. These changes could potentially have long term consequences if bones were broken often, leading to periods of decreased mobility followed by recovery until another bone fracture occurred. Previous experience with broken bones informed young adults' beliefs about the experience of fractures, but none of the young adults had personal or familial knowledge of osteoporotic fracture.

Subtheme #1: Weakness. Limitations to mobility were also seen as an experience of osteoporosis in a more generalized sense, which led young adult participants to perceive osteoporosis as weakness. Since bones are the framework of the body, a disease that caused bone to become brittle was believed to also weaken the body's structure. The idea of weakness was seen as a result of the disease process and the underlying cause of the fractures. Unlike the fractures, which restricted mobility in the short term, this sense of weakness was permanent,

gradual, and a contributing factor to the overall decline associated with having a degenerative bone disease. *“They feel slightly weaker. Like they are taking a step and they feel less sure”* (YA08).

3.1.2 Theme #2 Aging

All of the issues surrounding fractures were mediated by the role of aging. Osteoporosis was seen as a disease of older females and considered to be an expected part of the aging process. The changes associated with osteoporosis, such as restricted mobility, weakness, and frail bones, were viewed as matching the commonly accepted image of an older female. Osteoporotic changes were not viewed as inherently pathological because degenerative changes were part of the expectation for decline that came with aging. *“I associate it with aging anyways. It's something that for some people maybe isn't avoidable”* (YA08). This idea was ingrained in young adults through their own experiences with older persons, such as their grandparents, and through commercials and pop culture that reinforced the perception of older persons as physically compromised and osteoporosis as an inevitable part of aging. Young adults constructed osteoporosis as an unavoidable future problem caused by natural changes in bone that had no bearing or relationship to their current decisions. Prevention was placed in the sphere of older adults who were experiencing natural decline and young adults indicated they did not need to consider osteoporotic changes until their bone began to degenerate as well.

3.2 At-Risk Older Adults

3.2.1 Theme #1 Fractures

“Sure I'm taking calcium and vitamin D and getting a little bit of exercise here and a little bit of exercise there, but it's not like heart disease or cancer or something that you can really identify with unless you have someone close to you that, or you yourself, is diagnosed.” (ARW04)

Older women who were considered at risk of osteoporosis also viewed fractures as the defining characteristic of osteoporosis. *“I just think that it makes your body weaker and that you have to watch your moves because certain moves you can snap a bone”* (ARW06). These women were concerned about breaking a bone and compared it to their previous fracture experiences and the resulting effects on their daily activities. Fractures were seen as a painful inconvenience that would heal, were not fatal, and did not involve long term consequences. While osteoporosis increased the likelihood of fractures, even multiple fractures over a period of time were viewed as separate incidents, unconnected by debilitating sequelae. The women discussed osteoporosis in comparison to the “big ones,” namely cancer and heart disease, and constructed it as treatable if they developed it. *“I think about it. Take care of it with calcium and bone density every two years scans. And forget about it”* (ARW02,) Osteoporosis was therefore perceived as less concerning compared to a fatal disease.

Osteoporosis was viewed as fracture-centered and the experience of having osteoporosis centered on continuous prevention of fractures. *“If I fall I have something to hold me without my bone breaking so I don't have to go through any of that again”* (ARW 01). Prevention focussed on bone density tests, annual physicians visits, calcium-rich diets, and exercise. The women relied

heavily on screening tests, such as the bone density test, to identify potential problems and did not feel that other lifestyle changes were required until the bone density test or a physician indicated they were at increased fracture risk. Increasing dietary calcium, supplementation of calcium and vitamin D, and engaging in exercise were noted as important prevention activities, but were seen as less important than screening. Calcium and vitamin D were the only ‘treatments’ that were recognized by the women, but prevention was the focus of women who already had osteoporosis and who therefore needed to prevent fractures.

3.2.2 Theme #2: It Won’t Happen to Me

While acknowledging they were considered at-risk these women constructed osteoporosis as a distant threat that could not happen to them. *“I’ve always been active, but it’s something I really don’t think can happen to me type scenario”* (ARW03). When discussing risk, they made it clear that they did not consider themselves as risk. To them osteoporosis was associated with the image of a frail, weak, visibly ‘old’ woman that they saw as still removed from themselves.

3.2.3 Theme #3: Aging

At the same time, these women recognized a relationship between age and osteoporosis. They saw themselves as entering a period of increased risk because they were now over 50, which was seen as the marker of increasing health decline. As a disease characterised by decline, osteoporosis was perceived as a normal part of the aging process, since it was understood that the body function declined with age. Though these women also saw osteoporosis as a disease of older women, they still did not see themselves as high risk. Osteoporosis meant they needed to be more conscious of their activity and careful to avoid falling; however, they did not feel that osteoporosis would pose significant impediments to their lives because they were already over 50 and it was expected that they would have to be more careful anyway. *“I just go slow. I haven’t fallen or nothing. I am very cautious”* (ARW08). The projected experience of osteoporosis was seen as being very similar to their current at-risk experience and would involve greater care and concern about the body.

3.3 Women with Osteoporosis

3.3.1 Theme #1 Fractures

“I felt betrayed. Really, because you assume that your body is going to keep you forever. I think this is probably left over from the days when you're younger and you think of yourself as a potato rather than a donut.” (OW09).

Subtheme #1: Fear. All nine of these women had been diagnosed with osteoporosis, but only three reported osteoporosis-associated fractures. While not all of them had a fracture, their experiences of osteoporosis were still constructed around fractures because the fracture event became the catalyst for a more psychosocial focus. Heightened awareness and fear were both discussed as reactions to the actual fracture (for those with fractures) or simply the potential for a fracture (for those without). *“Instead of being reckless, you look. I guess that’s a fear, but it’s not an overwhelming fear. I just want to be more aware of my surroundings. A precaution”* (OW02).

Fear and awareness had origins in the realization, through the osteoporosis diagnosis, of an invisible weakness within their bodies that they could not measure or monitor. Women who had already had fractures were afraid of the potential limitations, specifically a long healing process that can limit movement. It was not just the restrictions during the healing process that the women feared, but also the changes in behaviour that came from knowing their bodies were fragile. One woman recounted how after her first fracture she would only sit with her back to the wall in restaurants because she was terrified someone would *"hit her back"* and cause another fracture. Women who had not experienced fractures themselves referenced the experiences of friends or family. One woman explained the experience of her mother-in-law as one of anger and frustration as she was unable to lift her arm to remove her teacup from the cupboard and required assistance from her family for daily tasks. The loss of independence as the outcome of a fracture contributed to her fear of fractures and potential changes in behaviour.

Subtheme #2: Awareness. To other women, the potential for fracture created a greater sense of awareness that was similarly based on the knowledge that their overall structure had been weakened and was now susceptible to damage from falls. These women did not see this awareness as a fear, but rather a heedfulness and increased attention to their surroundings. *"I'm walking my way to the garage and I'm just being very careful, but I wouldn't say I'm afraid"* (OW04). While women felt they did not change their behaviours, their descriptions indicated that while they would not avoid particular activities, they would alter them. For example, when going out in winter they would choose shoes with a grip, walk more slowly, or walk with a friend. The potential for fracture combined with this recognised physical weakness caused these women to think about their future actions when they would not have done so before they were diagnosed.

Subtheme #3: Pain. Pain was a central part of the fracture experience as well as a source of fear. For some women the pain was part of the everyday experience of osteoporosis, especially in the case of vertebral fractures, which often do not heal and cause chronic pain. One woman with multiple vertebral fractures described the experience as *"agonizingly painful"* (OW01). Even silent (painless) fractures were undesirable as they represented physical alterations in the bone that reinforced the sense of fragility.

3.3.2 Theme #2 Betrayal of the Body

This overall sense of increasing weakness and potential for fracture was associated with feelings of betrayal. *"I was devastated absolutely because I didn't think there was any cure because I worked in a nursing home doing activities after my job. And all I saw was all these little old ladies with the curve and I thought this is how I'm going to end up."* (OW01). The structural failure of the bone and resulting vulnerability was seen as an act of betrayal of the body. These women felt that they had behaved appropriately toward their bodies, consuming milk, exercising, and staying healthy and were angry and frustrated that their bodies had turned against them by breaking down in an invisible way. The manifestations of these unseen changes on their material bodies were also a source of disappointment, annoyance, and embarrassment as height was lost, kyphotic changes altered posture, and clothing no longer fit. One woman described her sadness as she had to exchange her high heeled shoes for flats when she could no longer balance properly and was concerned about falling.

3.3.3 Theme #3: Aging

The resentment they felt toward their bodies was mediated by their perception of osteoporosis as an expected result of aging. Osteoporosis was reflective of the aging process and viewed as an indication of age. *“When you’re in the age group you think ‘well I’m a multitasker I can handle this too.’ You don’t have too many choices”* (OW09). Decline and degeneration were accepted markers of aging and they viewed their diagnosis as an indication that they had entered the life stage of older women. The difficulties and lifestyle changes presented by osteoporosis were grouped with other changes to the physical body that were understood as inevitable markers of aging. Osteoporosis was interpreted as a more serious part of the process of aging.

3.3.4 Theme #4: Treatment-Centered

For the women with osteoporosis, their experience was treatment-centered. Bisphosphonates, the most widely prescribed treatment required a strict daily regiment. As a result, balancing life with medication was a constant struggle for these women and required them to make scheduling compromises in order to properly take their medication. Osteoporosis medication has a number of side effects, which caused additional fear of having a reaction. Medication was raised as a topic in response to all nine of the interview questions asked, underscoring the importance that medication played in their experience of having osteoporosis.

4. Discussion

4.1 Experience of Osteoporosis

The experience of osteoporosis was constructed differently across the lifecourse, but revolved around the role of fractures and associations with aging. All three groups viewed osteoporosis as characterised by fractures, but the role of the fractures to the larger disease process differed. To the young and at-risk adults the fracture was the entire event, albeit one that could occur multiple times. Using their own personal experiences of fractures they constructed them as limiting and painful, but ultimately short term. While the osteoporotic adults also indicated fractures as a defining feature of osteoporosis, they saw fractures as a catalyst for future problems, rather than the main feature of the disease. A fracture served as tangible evidence that a person truly had weakened bone and, for many women, made the disease real to them. Young and at-risk adults did not appear to be aware that not all fractures heal, whereas the osteoporotic adults made reference to the permanent changes and lasting pain that accompanied fractures. While fractures were a significant event for all groups, the meaning of osteoporotic fractures changes significantly throughout the lifecourse and belies the problems with young and at-risk adults using their own fracture experiences to extrapolate the experience of osteoporosis.

The construction of the osteoporosis experience by all three groups was rooted in their perceptions about bone composition and their knowledge of osteoporosis. Young adults saw bone as a static substrate and degeneration was the result of age as bone would be worn down over time with use, starting in the fourth and fifth decades of life. This meant that concern over bone health was not necessary until the end of middle age. At-risk adults were not explicit about bone growth, but they perceived osteoporosis to be something that could be attenuated or halted after

it had been developed. This translated into the belief that prevention was not necessarily required before bone was osteoporotic because it could be reversed later, while providing a rationalization for delaying engagement in prevention. The osteoporotic adults were aware that bone could be influenced throughout the lifecourse, but admitted that this was in hindsight and related to their increased knowledge of bone due to their diagnosis with osteoporosis. By viewing bone as essentially static, osteoporotic changes to bone become disconnected from decisions made during the entire lifetime. This perception results in osteoporosis being understood as an exclusive problem of old age and removes the onus for prevention until the appropriate age is reached.

The previous knowledge that individuals had about osteoporosis influenced their understanding or imagining of the disease experience. Young adults were aware of the basic facts surrounding osteoporosis, but most of this knowledge came from television and advertisements, not from formal education. At-risk adults were more aware of osteoporosis prevention methods, though they were concentrated on diet. While some had been screened for bone density, they had not discussed the disease or the reasons for the test with their doctor. The osteoporotic adults were fairly well-informed, but most indicated they had conducted their own research, motivated by their diagnosis. All three groups felt that osteoporosis had low visibility as a disease, compared to cancer or heart disease. Overall, the lack of detailed and accurate information about osteoporosis allowed the young and at-risk adults to construct the disease experience as a manageable minor impediment to life, rather than as the chronic, life-changing process that the osteoporotic women experienced.

The relationship between osteoporosis and age was a common theme and was a major factor in how all three groups understood the disease. Age was used by all groups to normalise osteoporosis by framing it as a disease of old age. By constructing osteoporosis as an expected part of the aging process the threat that osteoporosis poses is minimized and the lack of engagement in prevention is justified. Young adults not only normalised osteoporosis, but also relegated it to being a potential problem only in their distant future, reducing their perceived susceptibility. The at-risk women, who had selected age 50 as the threshold for old age, recognised that they were now considered at greater risk since, but felt that osteoporosis was a disease of even older age (they did not specify what age) and so did not consider themselves at risk.

Generally, the consequences of osteoporosis were framed either within the physical or psychological changes associated with the disease. Young adults focussed on physical changes as the locus of the osteoporosis experience. Their main concerns associated with osteoporosis were the limitations that it would pose to engagement in physically demanding activities (such as running or sports) or socializing outside of the home. Their projected experiences were informed by their own priorities and interests, which were not necessarily reflective of the concerns that might be expressed by older individuals with osteoporosis. Responses concerning physical limitations were tied to fractures and were focussed on short term incapacities during healing, which did not take into account the potential for slower or incomplete healing associated with older age and osteoporotic bone. Young adults also described a profound and constant sense of weakness associated with osteoporosis. These comments deserve specific attention as they were not mentioned by either of the other groups and suggest that young adults envisioned the loss of bone density as an embodied change that could be sensed by the individual.

The osteoporotic adults indicated pain was the greatest physical issue related to osteoporosis, but felt that the psychological issues surrounding the disease were of much greater importance. Only three of the osteoporotic women had experienced a fracture; therefore, pain and fracture were not significant characteristics of their experience. The diagnosed women also did not describe osteoporosis as limiting; they claimed treatment and medications made it so osteoporosis had not altered their lifestyles in any way, though they had sought out bone-specific exercise groups, changed their diet, pursued activity with greater awareness, and changed their daily routines around their medication. This contradiction speaks to the importance these women placed in preventing osteoporosis from becoming a limiting factor in their lives. Their reported experiences are broadly similar to reported experiences in the literature, both in osteoporosis and the chronic disease literature [15, 16, 18].

To the osteoporotic women the emotional changes that accompanied osteoporosis were the most concerning potential effects of the disease. They identified the potential future loss of independence and the ability to make choices about their activities as most threatened by osteoporosis. The embodied experience of osteoporosis had caused them to see their bodies as separate entities that, in becoming sick, had acted against them. There was a sense of alienation from their bodies, expressed through feelings of betrayal. This mistrust of the body had changed the experience of illness for these women and affected their relationship with their bodies.

Treatment was also a central aspect of the osteoporosis experience for the osteoporotic adults, whereas it was not mentioned by the young or at-risk adults. These non-osteoporotic individuals saw osteoporosis as prevention-centered and did not appear to be cognizant of potential treatments. The at-risk adults especially saw osteoporosis as something that could be “*taken care of*” (ARW02) with supplements and exercise. In this way they constructed osteoporosis as a disease that could be controlled, which allowed them to reduce the potential risk associated with osteoporosis. To the older adults, especially those without fractures, the treatment surrounding osteoporosis was a source of more concern than the actual symptoms. Treatment was a daily reminder of the disease and an integral part of the experience of being ill.

4.2 How Lived Experience Affects Prevention

Applying this information on how osteoporosis is conceptualised to the HBM can provide insight into the potential for engagement in prevention at different points in the lifecourse. When considering the severity of osteoporosis, all three groups constructed osteoporosis as relatively less severe than other diseases. Young and at-risk adults used age, the short-term nature of fractures, the lack of visibility of the disease, and the low mortality associated with osteoporosis to reduce the impact it could have on their lives. Similarly, the young and at-risk adults did not see themselves as susceptible. By removing the chronic nature of osteoporosis and normalizing it as part of aging, the symptoms become less like those of a disease and more like an expected decline with age. Additionally, the at-risk adults used a prevention framework that allowed them to see osteoporosis as a disease they could control, which made it less serious and themselves less susceptible. While osteoporotic adults understated the effects of osteoporosis on their lives, they did not see it as a controllable disease and were acutely aware of the potential problems it posed.

By reducing the perceived severity of and susceptibility to osteoporosis, motivation to engage in prevention is less likely. Young and at-risk adults were not motivated to prevent osteoporosis.

They did not see osteoporosis as severe or themselves as susceptible and their beliefs about osteoporosis were grounded in their own lived experience that viewed age-related changes as normal and expected. While the osteoporotic adults were managing their osteoporosis through diet, exercise, and medication they had not done so before being diagnosed.

5. Conclusion

The stage of the lifecourse which an individual currently inhabits affects how the experience of osteoporosis is conceptualised. Understanding individual experiences is important for supporting patients as well as designing osteoporosis prevention. As experiences change throughout life, so does interest in engaging in prevention. Prevention is needed to lower the risk of osteoporosis, but the ways in which the young and at-risk adults frame osteoporosis makes them less likely to engage in prevention and lower the future rate of osteoporosis. Young and at-risk adults need to be made aware of the actual lived experience of osteoporosis in order to bring their beliefs closer to those experienced by the women who have osteoporosis.

While osteoporosis education is a major aspect of prevention, most education focuses on well as diet and exercise. Since many of the beliefs about osteoporosis discussed here are rooted in perceptions of osteoporosis as fracture-centered and age-related these represent important areas for improving on educational messaging. Aiding young and at-risk adults to relate osteoporosis to their own lives and integrating the personal experiences of women with osteoporosis that focus on lived experience rather than clinical facts may have the potential to alter perceptions of osteoporosis so that prevention is adopted at younger ages.

Author Contributions

These authors contributed equally to this work.

Competing Interests

The authors have declared that no competing interests exist.

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