

Learning to Live with Osteoporosis: A Metaphoric Narrative

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Abstract

A philosophical hermeneutic research approach was chosen to explore the meaning of living with osteoporosis, a degenerative bone disease, through the narratives authored by twelve participants. The findings provided in this article offer a perspective of how one's shifting sense of self-renewal was expressed through osteoporosis-specific metaphors, which explicated a transformative process of how one learns to live well with osteoporosis. Three metaphors were identified and interpretively named the *shattering*, the *surrendering*, and the *dance*. Consideration was given to how an interpretation of these findings, through metaphor, may benefit others living with osteoporosis, and how those diagnosed in the future can benefit from shared understandings and conversations about the meaning of living with osteoporosis. As persons endeavored to make meaning of living with their illness, metaphors provided a useful common ground and invitation for discussion, story-telling, and the development of supportive relationships – all implemented as educative methods to positively transition the impacted persons' physical, emotional, and social traumas toward the possibility of self-renewal.

Keywords

illness narrative, osteoporosis, metaphor, patient experience, philosophical hermeneutics, transformational learning theory

Language is the fabric that weaves individual lives in and out of the lives of others.
(Hovey & Paul, 2007, p. 58)

Osteoporosis is sometimes called the silent thief because it steals-away bone mass without any discernible symptoms (Osteoporosis Canada, 2011). However, over time, when this illness manifests through its diagnosis, or from the first fracturing of the person's bones, its capacity to disrupt and indiscriminately

invade multiple dimensions of one's health is often overwhelming (Crossley, 2003; Hovey & Paul, 2007). When we are in good health, we take for granted our capacity to engage, move, work, socialize, and play almost effortlessly and without concern for active participation within our personal, physical, social,

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and relational worlds (Hovey, 2012). However, a diagnosis of osteoporosis, with or without a bone fracture, can dramatically change one's sense of self-efficacy and alter the ability to meaningfully participate in our lives (Cripe, 2009; Hovey, 2006).

Illness disrupts our lives and creates new personal narratives to describe how we engage in, and interpret, our world. From the inconvenience of a common cold or flu to a diagnosis of cancer, cardiovascular conditions, diabetes, or osteoporosis - each presents a unique and specific set of reactions, perceptions, and expectations (Fife, 1994; Frank, 2009; Hovey, 2006; Hovey & Paul, 2007; Hydén, 1997; Nielsen, Brixen, & Huniche, 2011; Shapiro, 2011; Solimeo, Weber, & Gold, 2011). The diagnosis, treatment, and possibility for recovery are contingent on multiple factors such as the extent and severity of the illness, the degree of vulnerability of the ill person, and possible restrictions for social engagement with others. Communication within the context of the health care provider-patient relationship necessitates finding a common ground where the medical practitioner and the patient and family can achieve an understanding of what is happening to them.

In this article, we describe a philosophical hermeneutic inquiry that explored the experience and meaning of people living with osteoporosis. Our intention in this article is to offer insights and understandings from participants who have learned, or are learning to live, with osteoporosis, and with these insights, to better develop health care education, promotion, and practice initiatives that enhance the lives of people living with osteoporosis. We explored the transformative process of learning to share the collective understanding of others' illness experiences, and provide first-hand narrative accounts of persons living with osteoporosis. These perspectives offer new

insights into how people learn to live with this chronic illness and help to interpret key lessons for those providing care (Cripe, 2009; Hovey, 2006; Hovey et al., 2011). For persons living with osteoporosis and their families, the sharing of osteoporosis stories offers a possibility to connect with others - both pragmatically and relationally - about the meaning of living with this illness (Charron, 2006; Hovey & Paul, 2007).

Background

Persons living with a diagnosis of osteoporosis can be regarded as an illness to be treated, "within a medical system whose currency is diagnosis, difference is often defined through disease" (Metzl & Poirier, 2004, p. vi). In addition to the physical treatment of the illness, those impacted have also identified as persons living in a world comprised of relationships, families, social-relational networks, educational endeavors, work, activities, and self - precariously hinged on the hope for a healthy and meaningful future (Black, 2002; Hovey, 2006; Smith & Sparkes, 2008). Consequently, conversations about the impacts of osteoporotic symptoms on one's physical well-being also commonly include references to the social, relational, and personal implications of osteoporosis on their previously-known ways of living their lives (Hovey, 2006; Metzl & Poirier, 2004).

Having osteoporosis means that it is always on my mind- and with the need to be careful, but sometimes you get thinking about something else and you start to do things as you always have and then you think: "Should I be doing this?"

The above quote from a participant illustrates the transition from being diagnosed with osteoporosis to living under constant vigilance with previously-taken-for-granted activities, in order to prevent further injury

and suffering. Osteoporosis can become a constant concern and through and its expression, the illness narrative helps in humanizing the experience (Frank, 2009; Tamas, 2009).

As human beings we create narratives to interconnect and make sense of all aspects of our internal and external lives through humanizing narratives (Hovey, 2006; Hovey & Paul, 2007). Concerning illness narratives, Frank (2009) reminded us, "...that all aspects of life need narration. To be human is not simply to live a life but to reflect on that life by telling it in multiple ways to multiple audiences, throughout the course of our lives" (pp. 187-188). The illness narrative becomes part of our inclination to humanize illness, rather than enduring the "dehumanization that [osteoporosis] patients have experienced at the hands of some medical practitioners and in the cultural imagination." (DeShazer, 2009, p. 216; Hovey, 2006)

The illness narrative becomes an opportunity, cathartically and therapeutically, for the person telling their experiences to help locate the illness within their life context and to help in the process of learning to live with chronic illness and to engage in self-renewal (Fife, 1994; Lange, 2004; Rimmon-Kenan, 2006). Through the explication of illness narratives, the opportunity to learn with, from and about, those living with illness as a knowledgeable other person is created (Hovey & Craig, 2011). Engagement with, and learning from, people living with osteoporosis affords the means to incorporate their narratives as knowledge that informs healthcare, illness-specific education, and real-life priorities, providing support and hope during these new and confusing experiences for those following in the footsteps of being diagnosed with a similar illness. The illness narrative offers both general understandings of the traumas of being diagnosed with a serious illness, as well as a description of the illness' particular

symptoms and characteristics. The persons diagnosed with cancer, diabetes, heart problems, osteoporosis, and other illnesses will create narratives that are specific to their understanding and meaning of how their illness will influence the totality of their lives (Hovey, 2012).

Methods

The Participants

This philosophical hermeneutic research project took place in two major Canadian cities. Ethical approval was obtained from both the University of Calgary and the Calgary Health Region Ethics Review Board. Volunteer participants were recruited and after careful explanation of the parameters of the study, they signed an informed consent document. In-depth individual interviews were conducted with 12 persons; one male and 11 female participants. Participants' ages ranged from 32 to 83 years, with a mean age of 61.8 years. The length of time living with osteoporosis – by approximate date of diagnosis – was from 2 to 30 years among participants (mean of 10 years). The age of being first diagnosed with osteoporosis ranged from 30 to 65 years of age, with a mean of 52 years of age.

Research Approach

The philosophical hermeneutics approach engaged involved the selection of participants who could best inform a perspective on a particular topic and invite a new understanding of it. In philosophical hermeneutics, interpretation is an ongoing process that begins with initial understandings of the research protocol and continues through the interview process, transcription, and textual analysis. These understandings are finally explicated through interpretive writing. This approach relies on a deep engagement with the topic and textual data, and attempts to generate new or differ-

ent understandings through a circular interpretive movement from the narrative parts of the experience to the whole rather than extracting or codifying themes. Philosophical hermeneutic participant interviews are semi-structured and conducted in a manner such as, to allow the meaning of the content and context of the experience to be fully expressed from the participant's perspective, to remain the central topic of exploration.

When participants tell of their personal experience out loud- into the world- it joins with the common experiences of others (Davey, 2006; Gadamer, 1989; Kearney, 2003, 2011). The shared collective of unique experiences lead interpretively to an understanding that is respectful of both the singularity of people and their experiences of an event, as well as what is commonly understood when interpreted among many others who have shared in a similar experience. Accounts of human experiences, however, are always interpreted from the participant's social-cultural, historical, and other specific characteristic perspectives. The individual narrative becomes part of the common history of the participant group by showing how one narrative account is an instance of something that can be more commonly understood. It can be stressed, however, that research findings and current understandings are always only provisional to further interpretations. The philosophical hermeneutic research process is inclusive of other perspectives and understandings about a topic. The consequence is that, as narrative texts are read and re-read, they open up other possible interpretations and new understandings. Kearney (2011) wrote that hermeneutics:

...[r]efers to the practice of discerning indirect, tacit or allusive meanings, of sensing another sense beyond or beneath apparent sense. This special human activity may in turn call for a method of second

order, reflective interpretation involving a process of disclosing concealed messages, either by a) unmasking covered-up meaning (hermeneutics of suspicion) or b) by disclosing surplus meaning (hermeneutics of affirmation). (p. 1)

Metaphor as Common Ground

Being diagnosed with an illness such as osteoporosis turns lives upside down. Understanding a person's unique experience necessitated the consideration of a three-part relationship, where one person comes to an understanding with another, engaging with that second person about a topic or conversation, which consequently leads to a new third aspect of the relationship: a shared understanding of the topic common to both participants. This is the work of Gadamer's dialogical hermeneutics: when two people understand each other, they always do so with respect to something and, in this project, the something - - the topic being understood - - was the experience of learning to live with osteoporosis (Gadamer, 1989). It is through an interpretive process, where the experience of the individual narrative becomes located within others as a collective, that reveals the commonalities within the illness experiences of others and contributes to the collective experience of something through narrative and conversation (Davey, 2006; Frank, 2009; Kearney, 2003).

The experiences of the research participants presented in this article were articulated through interpretations of their illness experiences in order to create a common ground for the person and medical practitioner, and enhance the possibility for understanding of such a complex topic (Gadamer, 1989; Hovey, 2012; Lakoff & Johnsen, 2003; McCrickerd, 2000; Sturmberg, Martin & O'Halloran, 2010). As Gadamer (1989) stated,

...if a person transfers an expression from one thing to the other, he [she] has in mind something that is common to both of them; but this in no-way needs to be generic universality. Rather, he [she] is following his [her] widening experience, which looks for similarities, whether in the appearance of things or in their significance for us...this is its fundamental metaphoric nature. (p. 429)

The utility of metaphor provided a vehicle in which the common encounter of living with osteoporosis could be represented within a context that was representative of the unique experiences shared by the participants (Hovey, 2006; 2012). These experiences included the reality that an intended, expected, and anticipated life was interrupted by an unexpected, unplanned, and unwelcomed illness. Osteoporosis became a serious disruption from a normal and predictable life journey to a transformative passage that involved suffering, courage, and commitment toward healing and self-renewal (Gadamer, 1996; Hovey, 2006; Shenk, Davis, & Murray, 2008).

Findings

Transformational Journeys: Diagnosis to Self-renewal

Chronic illness may “reduce a person to an exhausted heap, sunk into a sofa or a bed, helpless, weighed down by the unbearable weight of flesh, bone tired” (Caputo, 1993, p. 208).

I guess it was anger, I don't know, maybe depressed; I quit the gym and I stopped exercising and I had been exercising- you know- for twenty-five years and then I ended up like this. So I just said 'forget it' and I stopped everything and I gained weight and I led a much more sedentary lifestyle now. I think that is all because I

was very upset and I didn't talk about it with anybody.

Shattering. A participant recounts the traumatic and disorientating moment of finding out that she had osteoporosis: “*You know undoubtedly when you are first diagnosed it is very traumatic. Have you ever seen Snow White and the Seven Dwarfs? Do you remember when the queen diverted to the witch? She looked exactly how it feels.*” Certainly, this participant was not describing a transformation in her appearance similar to that of the witch in the story; rather, in that moment, her quote provides insight into the powerful influence of her diagnosis in distorting her image of self. The participant described her situation emotively through metaphor, as a means of interpreting a wide range of experiences, which were concerning changes to their life since their diagnosis of osteoporosis. Participants described the *shattering* effect of osteoporosis, not only of their own physical conditions, but also the impacts of diagnosis on their emotional and social-relational conditions (Hovey, 2012). “*I feel like a stupid, little old lady. I don't think of myself as a little old lady but mincing along [on an icy path] trying to make sure that I've got my foot squarely planted so that I'm not going to take a topple.*” In this case, the participant deals with both a new perception of herself of becoming “*a little old lady*” who now must be extremely cautious as she walks with uncertain footing, with a topple becoming a frightening and life-altering concern. A fracture sets into action several life-altering changes created by pain, possible deformity, social isolation, and an altered sense of identity (Black, 2002; Petrie & Weinman, 2006; Vitacca, Isimbaldi, Mainini, & Melazzini, 2011). “*I am sixty-three and I just turned sixty-three, but I did not think that 'old' happened, until you are eighty- and so I didn't intend to think about it [ageing] for a while.*” Consequently, the explanation of these journeys provided a por-

trayal about the complex series of progressions, adaptations, and new learning told by the participants. Another participant detailed: *“It is shattering when you are first diagnosed; you think, My God! I mean most people have this vision of the little old (osteoporotic) woman and the pain is tremendous.”* Metaphorically and practically, the experience of osteoporosis began with a *shattering* of bones, which represented the biomedical treatment of the illness, as well as how it influenced and shattered the social-relational aspects of participants’ lives. The *shattering* was not just about fracturing a bone but also being forced to live their lives differently as the participants became overwhelmed by fear, apprehension, and rapid changes to their perception of self and social identity (Crossley, 2003; Hovey, 2006; Hovey & Paul, 2007; Kearney, 2003; Smith, & Sparkes, 2008;). There was also the accumulated frustration that came from living for many years with something unnamed before their osteoporosis was diagnosed and treated.

It was traumatic! I was really upset because I could not ski and then I broke my ribs around that time too and so that further indicated that I had osteoporosis. Then I broke two toes last year and I either have a broken or cracked rib right now so I just know- you know- every time one of these things happens it’s more loss and so you have to grieve.

Some participants described their initial fracture(s) as a complete surprise: *“The fall was nothing.”* They were unusual: *“I was only lifting a box that I had always lifted;”* a minor fall or a sudden, insignificant turn that resulted in a painful and disabling fracture. Medical intervention provided crucial care after the shattering; healthcare practitioners eventually made the correct diagnosis, which then led to the appropriate treatment that promoted healing and the future maintenance

of their bone density. One participant provided an account of the seriousness of osteoporosis; not the illness per se, but the pain associated with undiagnosed fractures: *“I fell down one winter and I had to lie in the snow bank because I could not get up. Every time I tried to get up, the pain was excruciating, and I would pass out from time to time. I thought this was a really dangerous situation, the wind was howling like mad, coming across the driveway onto the lane and sidewalk, and I was getting covered with snow.”* Although these participants’ medical needs were eventually met, finding support for their psychosocial needs was more difficult or nonexistent. A sense of not being heard resulted in stress, depression, and frustration, all of which have been felt by many individuals when time was not taken to fully explain the situation.

One of the other things that stressed me [because of osteoporosis] was regarding my grandchildren. I can’t lift too much and I didn’t have it [osteoporosis] with the two oldest grandchildren, but the two youngest, I never related to or bonded quite as close to them because I could not lift them up or cuddle them.

The implications of being diagnosed with osteoporosis, with or without fractures, meant the lives of these participants were shattered, altered, and devastated. *“I had no understanding of what I should be doing: ‘How can I help myself?’ I had no idea...”* As well, pain medications had effects, *“I find if I take too much pain medication it does go to my head. It makes me feel blocked.”* The trauma of the diagnosis and fracturing were overwhelming conditions of the shattering. In this phase, the metaphor of being and feeling shattered, predominate as the biomedical aspects of the illness are at the forefront for the patient.

Knowing darn well if I slip and land on my butt I’m going to be two inches shorter

when I get up because it is mostly my spine that is really bad. In addition, it was just that feeling of 'I can't be like I used to be.'

So influential is pain on us that we withdraw from all external experience of the world. Every culture knows something of the profound internalization involved in suffering and the endurance of pain. Here we face real difficulty, which is at the heart of learning to live with osteoporosis: the pain, fear of fractures, and an uncertain future (Gadamer, 1996; Hovey & Paul, 2007; Vitacca et al., 2011). Someone's suffering from the pain and discomfort of osteoporosis can be amplified by their sense of loss-of-self, where a person living with a chronic illness witnesses a previously held concept of "self" dissolve into another, less positive vision (Elofsson & Ohlen, 2004; Hovey & Paul). People without the capacity to develop an equally valuable and meaningful alternative self-concept may be more likely to succumb to the powerful emotions associated with loss of independence, social isolation, perceived changes in social interactions, and thoughts of being a burden to others (Hovey, 2006; Vitacca, et al., 2011). Thinking about the self in this negative light creates profound emotional trauma and suffering that is not often recognized or purposely addressed within the biomedical view of the patient.

The process of learning to live with osteoporosis involved a transformation from the ill patient to person living with osteoporosis. The initial focus on the physical manifestations of the illness - the *shattering* - centered on the humanistic, social, occupational, intellectual, emotional, and environmental aspects that challenged the participant's participation within their day-to-day of being-in-the-world.

Surrendering. The next metaphoric interpretation revealed a second common experience

that the participants identified as a critical period of transition as people learning to live with osteoporosis. This became a *surrendering* to the implications of osteoporosis as a life to be lived differently. This is not a negative *surrendering* as in giving up hope or losing a battle; rather, it means giving in to the functional reality of their situations with the inherent difficulty and uncertainty of attempting to negotiate and piece fragments of their lives back together as different. The capacity to let go of previously-held perceptions of oneself enabled the consideration of new possible ways of being in the world (Rossiter, 2007). The participants who *surrendered* were able to consider and internalize new possibilities for themselves. During the *surrendering* phase, adaptation to change became the key element that influenced the reconstruction and perceived quality of their lives. Faced with limitations, it became essential to make new experiences and activities meaningful. The pre-osteoporotic world needed to give way to the present. The familiar, anticipated, and expected day-to-day life was reassessed and a new perception of quality of life negotiated. *Surrendering* to that which could not be changed opened up new possibilities. For one participant, working through living with osteoporosis meant meeting a patient advocate supporting others living with osteoporosis.

I met someone, a person named EM [an osteoporosis patient advocate] who was doing a walk across Canada. My company was sponsoring her. I helped with the walk, got to meet EM and speak to her, and got myself straightened out. She helped me to put things into perspective - what I should be doing, how I could do better. Well, it was very fortunate that I came to this understanding because EM opened up for me a different and more hopeful vision of what it means to live with osteoporosis.

Personal self-renewal is contingent not only on learning how to manage the physical aspects of osteoporosis but also the other dimensions of health such as, emotional, social, occupational, environmental, intellectual, and spiritual implications (Hovey, 2012). For another participant, finding a way to renew her sense of participation was through the acknowledgment that she could no longer be a physical gardener in the way she knew prior to living with osteoporosis. The substantial demands of gardening would be too risky. However, her surrendering provided an alternative means to continue her passion for gardening, which was to teach others.

It is always a loss, but, I guess during my life I've had to cope with loss- so you know you get quite good at it and so I said to myself, 'I'll find something else to do,' and I'll belong to the 'Green Thumbs' which you know we work in the greenhouses and we have a great time and I still do volunteer work teaching others how to garden.

The transformational process is not a passive one as this participant explained: *"The patient has to take charge. As an osteoporosis patient, you must take charge of your health, get all the information you can and then put it all together as a lifestyle for yourself. And it seemed to work well for me."* This participant's *surrendering* to the reality of her osteoporosis reflected her transition to becoming an empowered patient: *"Patients don't understand - they think they have to be told what to do, they have to be compliant. I can be compliant, but I am not, because I question why I am doing anything. I don't do something unless I know why."* The transformation of persons from *shattering* to *surrendering* meant finding meaningful ways of re-engaging their world. The transition between these phases is not absolute, as the person living with osteoporosis may find himself or herself cycling

back and through each of these phases. Although for the person living with osteoporosis a new fracturing of a bone would undoubtedly provide a possible setback within this process, the event is generally not new. As such, their accumulated personal and shared experience of living with osteoporosis and the gathering of valuable lessons and resources over time can help them to prevent and/or cope with future fractures when they occur.

Although the chronic illness cannot be healed, nor is full recovery from the illness a possibility, the person will often find a means to contextually re-interpret and re-negotiate their life with osteoporosis. Life does reconcile with the illness, the pain becomes increasingly manageable, environments are altered for safety, relationships change and evolve, and the implications of living with osteoporosis are no longer unknown and uncertain. Although the symptoms of osteoporosis may manifest for the person living with osteoporosis, the *surrendering* transitions them into a life where the illness is not always at the forefront of the person's day-to-day world. When the person learns to live with osteoporosis, it creates a partnership with the illness, one not by choice but through practicality, in which they can begin to move together in the world.

Dance. The *dance* represents a transformation from the initial *shattering* of the person's life, through learning to work with osteoporosis, toward negotiating a partnership with the illness. The *dance* metaphorically represents the movement toward self-renewal through a dance with a new partner: osteoporosis. Although the illness can only be managed but not cured, it does not have to pre-occupy every moment and life-event within that person's life.

I have had to re-create my independence [from osteoporosis] in a different way.

You have to be really creative. For example, I used to go cross-country skiing with a very nice group of people; I had to give that up so I had to find some substitute. I now go for walks and swim with another group of people. And I found that I had to substitute activities rather than cut out activities. You have to substitute what you liked to do with something else that you really like to do. The key is to find something else that is going to give you a sense of satisfaction from that activity.

This participant's description of what it means to willingly and mindfully let go of certain activities (*surrendering*) in order to discover new and meaningful others, is an example of the person's transformation to new ways of life that may be better suited to living with osteoporosis. Several participants also talked about the "gifts" of living with osteoporosis:

The gift of very great friendships; I met so many wonderful people because of my osteoporosis. While working with Osteoporosis Canada, many of us supported each other and created a strong network of women helping others. We were a very experienced group, sharing what we knew and experienced about osteoporosis.

Giving back to others became an additional aspect of this transformational phase for many of the participants. One became an advocate and mentor to her family, friends, and others by telling as many people as possible about her diagnosis and what she has learned during her experiences.

As a result of my unexpected diagnosis, I called my sisters who are both younger than me and said 'Listen, look at me. I'm the sign of health...' where the both of them are not and nowhere as healthy as me. 'And I've got osteoporosis- so you

better start pushing to find out if you got it.' Well sure enough, they have it (osteoporosis) and they have it worse than me and they are younger than I am. A relief... in that I was able to help them get onto the path of health.

Characteristically, the *dance* meant a transition and 'letting go' of some aspects of pre-osteoporosis life toward other possibilities, in order to be able to consider a new possible self (Rossiter, 2007; Shenk et al., 2008). "*You can choose to dwell on your losses, or you can choose to do something positive. There are things I will never be able to do again. I would love to go skating, or play golf. My husband and I used to golf all the time. Now I am scared to death to do it - - one mighty swing and I am back to where I was.*" The idea of being cautiously attentive to one's external world became extremely important. The *dance* with osteoporosis entailed (re) negotiating an altered future for many, including increased vigilance to the dangers present in their external environment, while finding new ways to engage in life. "*If I choose to do more positive things, assessing the risks of what I do, I also choose to know what my losses have been and say, 'Okay, but I can also still do so many things'.*" Living well with osteoporosis means becoming a partner in the *dance* of life, no longer being led by the disease.

Discussion

The physical symptoms associated with osteoporosis present a particular set of new restrictions, challenges, and acquired limitations for those affected. The transformative aspect of self-renewal begins with physical considerations because pain alienates one from oneself (Gadamer, 1996). For the person living with osteoporosis, pain became an ever-present fear and substantive obstacle on the journey to self-renewal. As one participant shared, "*The days I'm in a lot of pain, I just withdraw. I*

just lie down and when you are not yourself, so you tend to withdraw." Gadamer (1996) explained that, with

... pain, we cannot see paths and solutions in advance, yet we must ask ourselves if there will not always remain new possibilities. We encounter for example the loss of personhood. This happens within medical science when the individual patient is objectified in terms of a mere multiplicity of data. But the question is whether the unique value of the individual is properly recognized in this process. (p. 81)

A person suffering with the pain and discomfort of osteoporosis may often realize that the physical symptoms can be amplified by one's sense of loss of self (Black, 2002; Elofsson & Ohlen, 2004; Hovey, 2006). Those who lack the capacity to reconceptualize and reconfigure an equally valuable and meaningful self-concept are more likely to succumb to the powerful emotions associated with a loss of independence, social isolation, perceived changes in social identity, and the perception of becoming a burden to others (Vitacca et al., 2011). Thinking about oneself in this negative light can create profound emotional trauma that is not often recognized within the biomedical view of suffering (Black, 2002; Charmaz, 1983; Hovey & Paul, 2007; Smith & Sparkes, 2008; Tamas, 2009).

The findings from this research study can provide insight into the transformative aspects of people living with, and working through, osteoporosis in order to re-engage with their lives as meaningfully as possible. This re-engagement enlisted a process of critical reflection, in which transforming one's perspective provided the opportunity to create new understandings of how one adjusts to living with osteoporosis and facilitates a process of self-renewal. In this regard, the process of

learning to live with osteoporosis was described metaphorically as the *shattering*, *surrendering*, and the *dance*. This process, described using metaphoric images from participants' narratives, aligned closely with the tenets of transformational learning theory (Mezirow, 1995; Mezirow, 2000).

Transformational learning theory suggests that transformative learning occurs when individuals confront and engage in critical reflection on disorienting dilemmas such as a diagnosis of a serious illness. This traumatic, disorienting diagnosis for participants was the *shattering* and the pain of the physical, emotional, and social-relational impacts of chronic illness and cancer. (Brigham, 2011; Fife, 1994; Lange, 2004; Merriam, Caffarella, & Baumgartner, 2007; Mezirow, 2003) The transformation toward 'working through' osteoporosis meant an in-depth exploration of the illness' meaning to those affected with consideration of the roles, relationships and actions required to achieve a renewed sense of personal identity (Black, 2002; Hovey, 2006; Kearney, 2003; Smith, & Sparkes, 2008; Weston, Norris, & Clark, 2011) This process of working through their diagnosis, and finding meaningful ways to re-engage in self-renewal was identified by researchers as the *surrendering*. The kind of learning involved in this stage is one in which people living with the diagnosis of osteoporosis cannot return to how they once were. For such a renewal to occur, people learning to live with osteoporosis must negotiate and work through the chaotic disorder of their new worlds (Merriam et al.; Hovey; Lange; Mezirow). Researchers, through the metaphor of a *dance*, interpreted the result of the negotiation toward self-renewal, where the person living with osteoporosis negotiates a way to move through life. This *dance* is one of grace and dignity where the person engages the world differently but with a sense of self-renewal.

As biomedical diagnoses and treatment protocols for osteoporosis become more efficient and effective, our attention to the person learning to manage illness and its influences expands. Living with a chronic health condition means that even when it is being well-managed, it is always present. The transformation of a life – from fracture and/or diagnosis of osteoporosis, to a functional and favourable result – cannot be described as a linear trajectory from diagnosis to cure. Rather, the conversations described a series of interconnected experiences that have been – for the purpose of this article – defined as the *shattering* impact of diagnosis, the participant's *surrendering* to a new reality and the partnered *dance* of living a renewed and significant life. Learning to live with osteoporosis not only means learning to live with physical manifestations and symptoms but also with disquieted thoughts about the present and future. As the pain and discomfort subside, a space is cleared for the humanizing activities of self-renewal. As Rossiter (2007) stated,

... transition involves rehearsing attitudes and behaviours, visualizing oneself as having achieved a hoped-for goal represented by a possible self. Rehearsing and visualizing enable one to assess one's own comfort with moving in that direction. It is at this point that some possibilities are discarded and others more fully embraced. (p. 93)

The *shattering*, *surrendering* and the *dance*, as osteoporosis-specific metaphors, describe the transformative process worked through by all participants as part of their unique life experiences. As individuals who have shared in a common experience, each transformation and each step toward self-renewal depended upon a multiplicity of factors such as the severity of the symptoms; the individual's personality; experience with resiliency and adap-

tation; levels of education, social support, medical support; and age at the time of diagnosis (Hovey, 2006; Vitacca et al., 2011). Each individual experienced unique and widely-differing moments as part of living with osteoporosis, and yet the transformation towards a renewed reality - through the development of new emotional and social-relational experiences - was shared among all affected.

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Return to Person Centeredness

Patient/person centeredness calls for ethical consideration and an interdisciplinary approach to learn from those who have already experienced osteoporosis; to discover how they became able to live with their illness (Beadle-Brown & Mansell, 2004; Crossley, 2003; Hovey et al., 2011). This research project provided the means to ask questions and collect instructive narratives meant to complement and extend objective medical discourse of chronic illness, treatment, and recovery. While changes to one's physical characteristics and personhood occur slowly and over time, a diagnosis of osteoporosis can abruptly alter our perception of ageing (Beadle-Brown & Mansell; Black, 2002).

In this article, we provide insight into the experience of learning to live with osteoporosis from the personal perspectives of those who have worked through this process and desire to share their experiences with other patients, healthcare providers, and those working with older adults. Understanding the situation of others who have experienced

traumas can help to create the possibility for better treatment and care, as well as engagement that is softer, more sensitive, and more humanistic. Intervening, with a greater understanding of what it means to live with osteoporosis, can allow for specific educative and health promotional activities when, and as, they are needed. Encouraging patients' transformational progress toward self-renewal can not only enhance recovery, but also teach those living with osteoporosis to adapt to the shattering effects of chronic illness, not only to new symptoms and pains, but to a re-negotiated way of living in their world.

Conclusion

Within our socially-constructed perspectives about those who offer knowledge, information, and education concerning illness experiences, we frequently defer to healthcare and research experts and their understanding of the patient experience. Undeniably, healthcare experts' knowledge and understanding of illness and treatment are invaluable to patients' long-term recovery from the 'silent thief of bone mass.' What may be ignored in the medical process is that the person living with the illness truly becomes the expert of living with that condition. Other ways of knowing and understanding - which extend to the continuum of care - can only be gained with the first-hand experience of something that happens to us or to others. These new and different everyday experiences, narrated from patients as lay-experts, inform the ontological perspective of living with osteoporosis. We need to consider the experiences people accumulate throughout their illness as knowledge guiding the development of health promotion, education, and health care practices, to inform recovery strategies and person-centered practices that enhance the lives of people living with osteoporosis (Hovey & Craig, 2011).

The use of participant narratives to generate osteoporosis-specific metaphors provided an alternative and meaningful explication of the transformational process toward self-renewal experienced by persons living with chronic illness. Understanding the transformational processes (*shattering*, *surrendering*, and the *dance*) specific to this journey entails adopting specific learning and intervention practices that can anticipate and meet the patient/person's learning needs as they are situated within the process of self-renewal (Hovey & Craig, 2011).

Furthermore, we offer in this research that all people learning to live with osteoporosis are multidimensional and dynamic, rather than static and predictable, with the capacity to meet significant challenges throughout their lifetime. From this perspective, the research participants living with osteoporosis revealed a transformative process of self-renewal defined by the *shattering*, *surrendering*, and the *dance*; these metaphoric interpretations can provide others with the framework to engage in additional conversations about the meaning of living with illness, and the meaning of adapting to new ways-of-being.

We issue the invitation to other researchers to interpret and share the diverse experiences of people living with osteoporosis, relying on their expertise of living with a life-changing chronic illness. We should consider the experiences people accumulate throughout their lives as expert personal knowledge that may guide our approach to developing effective health promotion techniques, educational interventions, and self-management methods for those living with and those who will live with chronic osteoporosis in the future. Through careful listening to these experiences, educators, health care providers, and promotion experts can begin to come to an understanding that will inform healthcare practices from a humanistic perspective. On pa-

tient/person centeredness, Beadle-Brown and Mansell (2004) provided that “it is individualized, in that it is intended to reflect the unique circumstances of the individual person...in both assessing and organizing what needs to be done” (p. 1). In this study, a patient-centered approach for research provided new and different perspectives to inform and complement patient treatment protocols and practices going forward. By sharing the experiences of those living with osteoporosis with other patients, health care professionals, and educators, we can begin to truly understand the life-altering impacts of chronic illness, and allow others to follow in those well-trodden footsteps, softly and with purpose.

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The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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