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MANAGEMENT OF OSTEOPOROTIC VERTEBRAL FRACTURES: THE PATIENT'S PERSPECTIVE REGARDING THE NEED FOR INFORMATION, PROGRAMS AND SERVICES.

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MANAGEMENT OF OSTEOPOROTIC VERTEBRAL FRACTURES: THE PATIENT'S PERSPECTIVE REGARDING THE NEED FOR INFORMATION, PROGRAMS AND SERVICES.

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ABSTRACT

Approximately 1.4 million Canadians live with osteoporosis with over 530,000 in Ontario. Research suggests a relationship between osteoporotic vertebral fractures and a decreased ability to perform activities of daily living, an increase in overall level of disability, and ability to engage in leisure activities. How information and current programs and services relate to the needs of patients with osteoporosis requires further exploration. This study uses a phenomenological approach to explore the specific needs of individuals with osteoporotic vertebral fractures living independently in the community. Three focus groups were conducted with a total of nine participants recruited through the Regional Osteoporosis Clinic. An environmental scan of currently available programs and services in London, Ontario was conducted. Inductive content analysis was used to understand the women's needs for information, programs and services.

Findings suggest a discrepancy between participants expressed needs and currently available information, programs, and services. Results indicate that women perceive osteoporotic vertebral fractures through three lenses: journey to diagnosis, learning about the condition, and adapting to the condition. Three major gaps were identified including lack of linking a person to osteoporosis information, lack of programs and services for those with osteoporotic vertebral fractures, and health care system barriers. Findings from this study may inform future health promotion and service delivery strategies offered by the Osteoporosis Canada and the Ontario Osteoporosis Strategy.

Keywords: osteoporosis, vertebral fractures, needs assessment, programs and services

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Anti-resorptive medications:
Pharmacological agents used to stop the demineralization of bone.

Bisphosphonate:
A group of medications, called anti-resorptive, used to treat osteoporosis. They work by decreasing the activity of the osteoclasts thereby allowing the osteoblasts to work more effectively.

Bone Mineral Density (BMD):
Bone mineral density is a component of overall bone strength. Bone mineral density measurement is currently the most frequently used method for assessing future risk of fracture.

Bone Mineral Density Test:
A diagnostic test to determine the density or strength of bone by measuring density at the hip and lumbar spine.

Dual Energy X-Ray Absorptiometry (DEXA):
A method of determining bone density. It is considered the gold standard of diagnostic tools for osteoporosis by the World Health Organization.

Fragility Fracture:
A fracture that occurs due to a fall from a standing height or less. Also referred to as a low-trauma fracture.

Kyphosis:
A curving of the spine that causes a bowing of the back that in turn leads to a hunched back or slouching posture. Kyphosis is a key sign of spinal compression or vertebral fracture.

Osteoblast:
A bone cell responsible for bone formation, located on the surfaces of bone tissue where new bone is formed.

Osteoclast:
A bone cell responsible for the resorption of old bone.

Osteoporosis:
A loss of protein matrix tissue from bone, causing it to become brittle and subsequently fracture. It is characterized by low bone mass or poor bone quality that causes increased fragility and an increase in the risk of fracture. It is defined as a BMD measurement more than –2.5 SD below the young adult mean at the femoral neck or the lumbar spine.

Osteopenia:
A term used to describe low bone mass that is a value between –1.0 SD and -2.5 SD below the young adult mean value at the femoral head or the lumbar spine.

Peak Bone Mass:
Peak bone mass refers to the point at which bones have achieved their maximum strength and density. This happens at approximately age 16 in women and age 20 in men.

CHAPTER 1

INTRODUCTION

1.0 Overview of Thesis Chapters

This thesis follows a monograph format. Chapter 1 outlines this researcher's position within qualitative research paradigms. Chapter 2 outlines osteoporosis, literature related to the research topic, study purpose and research questions. Chapter 3 presents an overview of the methodology used for this study. Chapter 4 reports the findings and interpretations of this study. Chapter 5 provides discussion and outlines conclusions of this study and implications for future research.

1.1 Statement of the Problem

Osteoporosis is a condition in which, over time, bones can become thin and weak resulting in an increased risk for fracture. Osteoporotic fractures can result in pain, disfigurement, loss of independence, decreased quality of life, and even death, with a significant personal and financial impact (Wiktorowicz, Goeree, Papaioannou, Adachi, & Papadimitropoulos, 2001). Given global population aging, the prevalence of osteoporosis is expected to increase (Cummings, Cosman & Jamal, 2002). The most common osteoporotic fractures are of the hip, wrist, and spine (Osteoporosis Canada, 2008).

Management of osteoporosis includes appropriate diagnosis, medication and lifestyle changes. Lifestyle changes include physical activity, nutrition, and intake of calcium and vitamin D. Vertebral fracture, due to osteoporosis, is a condition that is often under-diagnosed and under-treated resulting in a significant care gap with respect to diagnosis and treatment (Lentle, Brown, Khan, Leslie, Levesque, Lyons, et al., 2007).

In 2005 the Ministry of Health and Long Term care funded an Ontario Osteoporosis Strategy to address the osteoporosis care gap. A component of this strategy is to disseminate information and develop programs and services to increase awareness about osteoporosis and provide resources for people living with osteoporosis. Funding for this strategy is provided, in part, to develop information, programs and services related to osteoporosis. In an effort to ensure the information, programs, and services are of value to the individual, it is essential to include their opinions and experiences in the development and evaluation of resources. It is important to understand what individuals living with osteoporosis need to assist them to live well, have a good quality of life, use the resources available to their benefit, and to help them better understand their condition. While there are questionnaires and surveys (Lydick et al., 1997; Cook et al., 1999) that investigate the quality of life of people who have osteoporosis and fractures, these assessment tools don't ask the individual "what are your needs?" and they don't focus on priorities of patients from the patient's perspective. The ability to conduct a "needs assessment" specific to chronic illness at the individual level remains a challenge (Asadi-Lari, Taburini, & Gray, 2004).

Richard Hovey's 2006 dissertation (What is it like to live with Osteoporosis?) provided recommendations for future research that included exploring patient education programs further. Expanding on this recommendation this research study aims to look at the needs of patients with osteoporosis and vertebral fractures. A review of the literature indicates the need for a needs assessment with strong psychometric properties. The first step in the creation of such a questionnaire involves a dialogue with those who have sustained an osteoporotic vertebral fracture (OVF). In order to understand the needs of patients with an OVF it makes sense to converse with patients and ask them to talk about their experiences. Through the use of a qualitative research methodology, the voice of the patient can be heard. Further, to truly understand patient needs we need to understand their experiences. Using phenomenology as a methodology captures the lived experience. By understanding the needs of women with vertebral fractures and comparing the current availability of information, programs and services strategies can be developed to address any gaps identified through this study.

The focus of this study is on women living independently in the community, who have been diagnosed with vertebral fractures, and their needs for information, programs, and services. As women with hip fracture tend not to live independently in the community their need for information, programs, and services would be different and based on the long term care home in which they reside. Women with hip fractures would not likely be able to access information, programs, and services based in the community. On the contrary, women with vertebral fractures tend to recover sufficiently to live independently in the community and need these community-based services to be able to live independently.

CHAPTER 2

OSTEOPOROSIS AND A REVIEW OF THE LITERATURE

2.0.0 Osteoporosis - Definition

At the National Institute of Health's consensus development conference in 1993 osteoporosis was defined as "a systemic skeletal disease characterized by low bone mass and micro-architecture deterioration of bone tissue with a resultant increase in fragility risk of fracture" (Consensus Development Conference, 1993). The increase in bone fragility greatly increases the risk of fracture (O'Neil & Roy, 2003; Siddique, Shetty & Duthie, 1999).

In 2001 the National Institutes of Health in the United States revised this definition as follows: "A skeletal disorder characterized by compromised bone strength predisposing a person to an increased risk of fracture. Bone strength reflects the integration of two main features – bone density and bone quality" (NIH Consensus Development Panel, 2001). While bone density is measured through a Bone Mineral Density (BMD) test, there is no objective measure of bone quality. Bone quality is assessed through a patient's history of fragility and fracture (Brown & Josse, 2002).

2.0.1 Osteoporosis – Incidence and Prevalence

One of the major risk factors for osteoporosis is being aged 65 and over. Globally, the population is aging and by the year 2050, it is estimated that the number of individuals over the age of 65 will be 1.55 billion (Gueldner, Grabo, Newman & Cooper, 2008). As a result, osteoporosis and related fractures are expected to increase substantially, which could result in a fourfold increase of the current fracture rate, with a growth from 1.66 million fractures in 1990 to 6.26 million fractures in 2050 worldwide

(Gueldner et al., 2008). Osteoporosis is thus a major public health concern because of an aging population, a potential increase in fracture rates and related costs. The International Osteoporosis Foundation (IOF) estimates osteoporosis currently affects 75 million people in Europe, USA and Japan (EFFO and NOF, 1997). On a global level, one in three women and one in five men will experience an osteoporotic related fracture (International Osteoporosis Foundation, 2008). A 50-year-old Caucasian woman has a lifetime risk of 16% of sustaining a vertebral fracture (Melton, Chrischilles, & Cooper, 1992).

The prevalence of osteoporosis in Canada is about 16% in women 50 years of age and older and 6.5% in men (Tenenhouse et al., 2000). In Canada it is estimated that one in four women over 50 years of age and at least one in eight men over 50 have osteoporosis with an estimated 1.4 million Canadians affected (Goeree, O'Brien, Pettit, Cuddy, Feraz & Adachi, 1996). Osteoporosis can result in a loss of independence and can seriously impact quality of life, and in some cases, complications of an osteoporotic hip fracture can lead to death (Wiktorowicz, Goeree, Papaioannou, Adachi & Papadimitropoulos, 2001). In Ontario it is estimated that over 530,000 individuals have osteoporosis (Osteoporosis Canada, 2008).

2.0.2 Cost Implications of Osteoporosis

The costs associated with osteoporosis are both human and financial. The financial costs are primarily associated with hip fracture resulting in hospitalisation, rehabilitation, and long-term care. The human costs are associated with a decrease in quality of life and increase in pain.

In Europe the number of osteoporotic fractures in 2000 was estimated to be 3.79 million with an associated direct cost of €31.7 billion Euros (International Osteoporosis

Foundation, 2008). The costs are expected to increase to €76.7 billion by the year 2050 due to an aging population. In the United States the direct costs associated with osteoporotic fractures were estimated to be between $12.2 billion and $17.9 billion in 2002, with an osteoporotic hip fracture estimated to cost the health care system $40,000 per hip fracture (Gueldner et al., 2008). Vertebral fractures have fewer hospital related costs compared to a hip fracture, however, they account for significantly more physicians' office visits (Gueldner et al., 2008) because patients with vertebral fractures are generally treated by their general practitioners.

The cost of treating osteoporosis in Canada is $1.3 billion per year with the majority of the costs attributed to long-term care and chronic care (Goeree et al., 1996). Acute care costs were estimated at $465 million and for long-term care and chronic care at $842 million (Goeree et al., 1996). The average cost of an osteoporotic hip fracture is $26,527.00 in the year of fracture (Wiktorowicz et al., 2001). The costs are slightly lower for individuals who are able to return to the community ($21, 385.00) and significantly higher for individuals admitted to long-term care ($44,156.00). Admission to long-term care doubles the cost of a hip fracture. The cost of vertebral fractures to the health care system in Canada is difficult to determine given they are under-diagnosed and under-treated (Lentle, et al., 2007). Vertebral fractures are a major risk factor in predicting future osteoporotic fractures (Lentle, et al., 2007; Cummings, Cosman & Jamal, 2002). While direct costs of vertebral fractures are difficult to establish, in 1998 it was estimated that costs associated with a vertebral fracture were $3,200 (Rosner et al., 1998). These direct costs do not include the indirect costs or the physical and psychological consequences of fracture.

2.0.3 Types of Osteoporosis

Osteoporosis is categorized into four types and includes postmenopausal osteoporosis, age-associated osteoporosis, idiopathic osteoporosis, and secondary osteoporosis (Cummings et al., 2004). Postmenopausal osteoporosis occurs at menopause due to a decrease in estrogen and progesterone production. Age-associated osteoporosis is caused by a slow decrease in bone mass due to increased bone resorption over the age of 65. Idiopathic osteoporosis is the term used when the cause of osteoporosis is not known. Secondary osteoporosis is osteoporosis that is caused by different disease conditions such as hyperparathyroidism, hyperthyroidism, or spinal cord injury. Inflammatory conditions arthritis, asthma, multiple sclerosis and systemic lupus erythematosus that can contribute to osteoporosis as well as eating disorders and sex hormone deficiency. Medications such as glucocorticoids, chemotherapy, and anticonvulsant medication can cause osteoporosis (Gueldner et al., 2008).

2.0.4 Bone Biology

Osteoporosis, regardless of etiology, reflects greater bone resorption compared to bone formation (Gueldner et al., 2008). Bone is a living tissue, containing a mixture of fibres and minerals, primarily calcium, that changes throughout a person's life (Cummings et al., 2004). Peak bone mass is achieved by age 16 in women and age 20 in men (Goldberg, 2004). Bone mass remains constant until approximately age of 30. After the age of 30 women and men lose bone mass at a rate of 0.5% to 1% per year (Osteoporosis Canada, 2008; Goldberg, 2004). Women have higher rates of osteoporosis than men due to the effects of menopause and a decrease in estrogen. Men achieve a higher peak bone mass than women by 30-50% (Stevenson & Marsh, 2007). There are four factors that affect a person's peak bone mass: genetics, hormones, nutrition, and physical activity.

Bone remodelling is the process where bone is repaired by removing old bone and forming new bone. There are four stages of bone remodelling – activation, resorption, reversal, and formation (Gueldner et al., 2008). Cells called osteoclasts remove old bone and are signalled in the activation phase to remove bone in the resorption stage. In the reversal stage osteoclast activity is suspended. In the formation stage cells called osteoblasts build new bone to fill in the cavity created by the osteoclast cells. The remodelling cycle takes approximately 3-6 months (Cummings et al., 2002). In osteoporosis, the remodelling cycle becomes unbalanced and bone loss can occur for a number of reasons including increased osteoclast activity and decreased osteoblast activity (Cummings et al., 2002).

2.0.5 Diagnosis

Prior to 1991, osteoporosis was diagnosed based on low-trauma fracture history. While bone densitometry was available in the early 1980's, it was not until after 1991 that it was widely introduced to assist health care professionals in diagnosing osteoporosis prior to a fracture in order to implement prevention strategies. The gold standard for diagnosing osteoporosis clinically is a Bone Mineral Density (BMD) test using dual-energy x-ray absorptiometry (DXA). The World Health Organization defines osteoporosis based on BMD test results. Osteoporosis is defined by the WHO as "a bone mass which is 2.5 standard deviations (SD) below the mean value of bone mass in young adults. Individuals who have in addition sustained one or more osteoporotic fractures are defined as having 'severe' or 'established' osteoporosis" (WHO, 1997, pg. 517). A T-score is "the number of standard deviations above or below the mean BMD for normal young adults" (Brown & Josse, pg. S3, 2002). Normal BMD is defined as a T-score between +2.5 and –1.0. Low BMD (previously referred to as osteopenia) is defined as a T-score between –1.0 and –2.5. Osteoporosis is defined as a T-score of less than –2.5. Severe osteoporosis is defined as a T-score of less than –2.5 and having sustained a fragility fracture.

2.0.6 Risk Factors for Osteoporosis

Osteoporosis Canada's 2002 Clinical guidelines (Brown & Josse, 2002) outline major and minor risk factors for osteoporosis. Individuals over the age of 50 with one major or two minor risk factors should be assessed for osteoporosis. An important part of osteoporosis risk reduction includes community education about risk factors. Major risk factors are shown in Table 1 below.

Table 1 *Osteoporosis Risk Factors*

Major risk factors	Minor risk factors
Age > 65 years	Rheumatoid arthritis
Vertebral compression fracture	Past history of hyperthyroidism
Fragility fracture after age 40	Chronic anticonvulsant therapy
Family history of osteoporotic fracture	Low dietary calcium intake
Systemic glucocorticoid therapy of > 3 months duration	Smoker
Malabsorption syndrome	Excessive alcohol intake (>2 drinks per day on a daily basis)
Primary Hyperparathyroidism	Excessive caffeine intake (4 or more servings of caffeine containing foods)
Tendency to fall	Weight of less than 57 kg
Low bone density apparent on x-ray film	Weight loss >10% of weight at age 25
Hypogonadism	Chronic Heparin therapy
Early menopause (before age 40)	

In addition to Bone Mineral Density score, risk factors are incorporated into risk for fracture (Brown & Josse, 2002). Risk factors for fracture include low bone mineral density, prior fragility fracture (a fall from a standing height or less that result in fracture), age and family history of osteoporosis.

2.0.7 Prevention and Management of Osteoporosis

Canadian clinical practice guidelines (Brown & Josse, 2002) advise the identification of risk factors, pharmacological treatments, nutritional interventions and physical activity as recommended osteoporosis management. The management of osteoporosis is directly related to the need for information, programs, and services because prevention and treatment focus not only on the use of medication but also on modification of lifestyle factors such as nutrition and physical activity. The information, programs, and services related to, for example, medication, nutrition, and physical activity allow individuals to make decisions about incorporating lifestyle changes into their treatment plan. The extent to which information, programs, and services are available in the community affects an individual's ability to access these resources.

Pharmacological treatments of osteoporosis include the use of bisphosphonates, calcitonin, hormone replacement therapy for post-menopausal women, and selective estrogen-receptor modulators (Brown & Josse, 2002). Bisphosphonates are anti-resorptive agents that are considered first line treatment for osteoporosis. They work by stopping further bone loss. More recently anabolic (bone-building) agents have been approved for osteoporosis treatment including teriparitide.

Non-pharmacological treatment of osteoporosis includes changes in diet, calcium, vitamin D, and physical activity (weight bearing and resistance exercises).

Nutritional interventions include diet modifications to ensure sufficient intake of calcium and vitamin D (Brown & Josse, 2002). For treatment of osteoporosis calcium and vitamin D are recommended to assist in building bone mass in conjunction with pharmacologic therapy (Brown & Josse, 2002). Calcium supplementation as a treatment for osteoporosis to increase bone mineral density remains controversial (Stevenson & Marsh, 2007).

Calcium is a mineral utilized by the body for numerous functions including bone formation (Gueldner et al., 2008; Osteoporosis Canada, 2008). Almost every cell in the body including the heart, nerves, and muscles uses calcium to function properly. Calcium is found in three places in the body – the skeleton and teeth, cells, and blood (Osteoporosis Canada, 2008). Calcium is critical for strong bones. It is absorbed from food or it is taken from the bones if there is not enough available through the diet so that it is always available to the body. The body regulates the amount excreted through the urine so that calcium remains in the blood stream and available to organs and cells (Osteoporosis Canada, 2008; Burkhardt, Dawson-Hughes & Heaney, 2001). The food choices that contain the highest amounts of calcium are dairy products including milk, yogurt, and cheese. The 2002 Clinical Guidelines for osteoporosis (Brown & Josse, 2002) recommend 1500 mg of calcium daily for men and women over the age of 50.

Vitamin D is essential to build and maintain bone mass, as it aids in the absorption of calcium. Vitamin D3 increases calcium absorption by 30% to 80% (Goldberg, 2004). There are limited sources of vitamin D available in the diet; as a result it is difficult to get enough vitamin D through diet so a supplement is recommended (Goldberg, 2004; Osteoporosis Canada, 2004). Current clinical guidelines (Brown & Josse, 2002) recommend 800 IU's of vitamin D per day for adults over the age of 50.

Sunlight exposure as a source of vitamin D is only sufficient during the summer months without the use of sunscreen. Vitamin D is also linked to falls prevention. It can decrease falls by as much as 22% in long-term care residents (Roux, Bischoff-Ferrari, Papapoulos, de Papp, West & Bouillon, 2008). Vitamin D administered with calcium has been shown to reduce fracture risk in individuals with osteoporosis over the age of 65 years (Cummings et al., 2002). Consuming a diet with appropriate amounts of calcium and vitamin D, and adhering to the recommendations, is considered a part of both prevention and treatment of osteoporosis.

Physical activity for both osteoporosis management and prevention is recommended for bone building, bone preservation, and falls prevention (McDermott, Zapalowski & Miller, 2004). Physical activity is recommended in children in order to achieve the highest peak bone mass possible (Brown & Josse, 2002). In adults, physical activity helps in maintaining bone mass, which is the key in preventing osteoporotic fractures in later life. Physical activity affects bone mass by placing a load on the bone. Over time this increased load increases bone mass. A decrease in physical activity alternatively leads to a decreased load on the bone and a subsequent decrease in bone mass (Cummings et al., 2002).

The most effective way to load bones of the spine and lower extremities is weight bearing. Weight bearing exercise includes activities such as walking, jogging, aerobics, stair climbing, dancing, skating, badminton, bowling, tennis, basketball, volleyball, and soccer. Martyn-St. James and Carroll (2008) conducted a meta-analysis of walking as a method of preserving bone density and concluded that walking had no significant effect on spine BMD, however, there was a significant effect of walking on femoral neck BMD. They also concluded that some forms of exercise such as resistance training provide focused skeletal loading and better preserve bone density in post-menopausal women. Resistance exercises involve moving objects against gravity to create resistance. They can include weight training with barbells, wrist weights, exercise bands, household objects, strength training, yoga, and push-ups. The most appropriate physical activity for osteoporosis includes a combination of weight bearing exercise and resistance exercise (Gueldner et al., 2008, Cummings et al., 2002). In order to build bone mass in a healthy adult, a physical activity program should consist of weight bearing exercise 3-5 times per week for at least 30 minutes per session and resistance training a minimum of 2-3 times per week. A minimum of 6-8 months is required in order to reach a measurable change in bone mass (Gueldner et al., 2008).

Certain movements are not recommended for people with osteoporosis. They include forward flexion with lifting, back extension, and twisting of the spine. In an older person the goal of physical activity is to maintain muscle strength in order to prevent falls as opposed to building bone mass (Stevenson & Marsh, 2008; Cummings et al., 2002).

2.0.8 Care Gap

There is an extensive amount of literature both in Canada and internationally that indicates a care gap with respect to osteoporosis diagnosis and treatment (Giangregorio, Papaioannou, Cranney, Zytaruk, & Adachi, 2006; Jaglal et al., 2006; Juby & Davis, 2001; Elliot-Gibson, Bogoch, Jamal, & Beaton, 2004; Follin, Black, & McDermott, 2003). The majority of individuals at high risk for osteoporosis who have already had at least one osteoporotic fracture are neither identified nor treated (Nguyen, Center, & Eisman, 2004). Patients who have sustained a fragility fracture, and their health care providers, frequently do not make the connection between fragility fracture and osteoporosis, despite available research that indicates a relationship, as a result patients are not diagnosed and treated for osteoporosis (Follin et al, 2003; Meadows, Mrkonjic, O'Brien, & Tink, 2007; McKercher, Crilly, & Kloseck, 2000). Adherence to medications is also known to be a challenge (Lau et al., 2008; Seeman et al., 2007). In order to address this care gap and provide more comprehensive care for those with osteoporosis an integrated-care delivery model for post-fracture care was developed (Jaglal et al., 2006). This model promotes improved acute hospital care communication between emergency departments and fracture clinics, and inclusion of family physicians in post fracture investigations in order to properly diagnose and treat low trauma fractures (Jaglal et al., 2006).

2.0.9 Osteoporosis and Fractures

The consequences of an osteoporotic fracture are significant and can result in disfigurement, lowered self-esteem, reduction or loss of mobility, and decreased independence (Osteoporosis Canada, 2008; Papaioannou et al., 2002). There are numerous studies linking osteoporosis and a decrease in quality of life (Adachi et al., 2001; Oleksik et al., 2000; Hallberg, Rosenqvist, Kartous, Lofman, Wahlstrom, & Toss, 2004; Papaioannou, 2006). The findings of these studies indicate a lower level of quality of life reported among those with osteoporotic fractures (both hip and vertebral) compared to those without osteoporotic fractures due to the level of disability hip and vertebral fractures can cause.

The influences of hip fracture on quality of life are significant. The average length of stay in hospital is two weeks, 30% of patients are discharged to in-patient rehabilitation units and 25% of community dwelling patients are discharged to long-term care following hip fracture. Only one third to one half of hip fracture patients regain their pre-fracture level of function, between 18% to 28% of older hip fracture patients die within one year of fracture due to complications, and admissions to long-term care double the cost of hip fracture (Jaglal et al., 1996).

Jensen and Harder (2004) suggested that vertebral fractures are the most common complication of osteoporosis that result in pain and/or disability and are generally unrecognised. The consequences of vertebral fracture include back pain, depression, fear of falling, and future fracture (Papaioannou et al., 2002). Vertebral fractures commonly result in a decline in quality of life due to loss of height, spinal deformity, protuberant abdomen, reduced lung function, weight loss, acute and chronic back pain, impaired mobility, and back-related disability (Papaioannou et al., 2002; Jensen & Harder, 2004). Other consequences of vertebral fractures include inability to perform activities of daily living, loss of independence, slower gait, and higher rates of reported disability (Lentle et al., 2007). Most recently a link between fractures and increased mortality has been established indicating that vertebral fractures increase risk of death, hence interventions are needed to decrease the incidence of vertebral fractures to increase survival rate (Ioannidis et al., 2009).

2.1.0 Measuring Quality of Life and Osteoporosis/Fractures

Measuring quality of life for those with osteoporosis has been conducted mainly through questionnaires, see below, for the purpose of assessing the relationship to medication, knowledge, and beliefs (Flood et al., 2006; Cook, Guyatt, Adachi, Epstein, & Juniper, 1999; Papaioannou et al., 2006). Several disease-specific questionnaires have been used to measure quality of life in those with osteoporosis including the Osteoporosis Quality of Life Questionnaire (Osteoporosis quality of life study group, 1999), Mini-Quality of Life Questionnaire (Adachi et al., 2001), Osteoporosis and You Questionnaire (Cadarette, Gignac, Beaton, Jaglal & Hawker, 2007), Osteoporosis Patient Treatment Satisfaction Questionnaire (OPSAT-Q) (Flood et al., 2006), and Qualeffo (Badia et al., 2001). While these questionnaires confirm a relationship between reduced quality of life and osteoporosis/fracture they do not further explore the needs of individuals in order to have a better quality of life. This question might be better addressed through a qualitative approach. More recently qualitative approaches have been used to measure osteoporosis knowledge and beliefs (Jachna & Forbes-Thompson, 2005; Jaglal et al., 2003; Giangregorio, Fisher, Papaioannou, & Zytaruk, 2007).

There are limited studies that have looked at quality of life using a qualitative approach specifically focusing on a need for information, programs, or services that could improve quality of life as indicated from the perspective of an individual with osteoporotic vertebral fractures. Clarke, Liu-Ambrose, Zyla, McKay & Khan (2005) used qualitative methodology employing interviews to look at how women with osteoporosis define health, quality of life, and well-being. They found that older women's (aged 75 to 86) ability to engage in leisure activities was the basis for their definition of good health, satisfactory quality of life, and well-being. The authors concluded that how women define health, quality of life, and well-being was reflective of Bury's (1988) concept of "meaning as consequence". As noted above, osteoporotic vertebral fractures impact the ability to engage in leisure activities and activities of daily living. The relationship between needs in order to improve or affect quality of life is not established.

By exploring needs for information, programs, and services it may bring some clarity or context to improving well-being.

2.1.1 Needs Assessment Research

The practice of community needs assessment and health needs assessment has been established for many years to better address the needs of the community at large (Gilmore, Campbell, & Becker, 1989; Robinson & Elkan, 1996). Public Health departments have practiced community and population health needs assessments extensively (Peterson & Alexander, 2001). Community organizations and health charities have previously undertaken assessments of the individuals they serve to better understand their needs and adapt information, programs, and services they offer (Gilmore et al., 1989; Krueger, 2008; Robinson & Elkan 1996).

A need can be defined as the difference between the present situation and a more desirable one (Gilmore et al., 1989). Bradshaw (1972) identified four distinct types of needs: normative need, felt need, expressed need, and comparative need. Bradshaw suggests that needs are by definition a subjective concept. Maslow's hierarchy of needs (1943) has five levels: physiological, safety, love/belonging, esteem, and self-actualization. Maslow suggests that the most basic needs (physiological) require fulfillment before an individual can satisfy those higher in the model (self-actualization). As a result of so many models the definition of a "need" with respect to a health care environment is challenging and complex (Asadi-Lari, Tamburini, & Gray, 2004).

In this study "need" is defined as a desire to access information, programs, and services that affect quality of life for women living with osteoporotic vertebral fractures. Much work has been done with respect to the hip fracture population in terms of costing of fractures and provision of health care services. Those with hip fractures tend to reside in long-term care or assisted living residences where access to services are moderated by health care professionals. However, those with osteoporotic vertebral fractures tend to live independently in the community and are less likely to have someone to help them access information, programs, and services. Research about patient services and needs specific to osteoporotic vertebral fractures is scarce.

2.1.2 Prevention and Education Programs

In order to help individuals with osteoporosis in Ontario and Canada cope with the disease and improve quality of life, several prevention and community education programs were established. In an effort to address the care gap the Ontario Ministry of Health & Long-Term Care created and funded in February 2005 the Ontario Osteoporosis Strategy. The goals of this strategy are to increase awareness, educate individuals in the community, improve post fracture care, and promote clinical guidelines. Prevention and education programs available in the community include support groups, Break Through training (an osteoporosis education program for adults), Canadian Osteoporosis Patient Network (COPN) support, and exercise programs (Bone Fit and MelioGuide). In an effort to reduce the number of falls several organizations have introduced falls prevention programs, including local health units and the Ontario Seniors' Secretariat. How these programs are created, utilized, funded, and evaluated is not well researched.

Self management programs have been developed around the world including the United Kingdom, Australia and United States to manage chronic disease conditions including osteoporosis (Barlow, Wright, Turner, & Bancroft, 2005; Francis, Matthews, VanMechelen, Bennel, & Osborne, 2009; Gold & Silverman, 2004). In Ontario there are self-management programs available regarding chronic disease such as the Arthritis Self-Management Program (Lorig, Mazonson, & Holman, 1993) which has an osteoporosis component. Programs specific to osteoporosis such as the POWER program (Gordon & Li, 2008) have been established however at this time there is no standardized self-management program specific to osteoporosis being delivered consistently in Ontario.

2.1.3 Needs Assessment Questionnaire

The use of needs assessment questionnaires has more recently been applied to a health care environment. Asadi-Lari, Packham, and Gray (2003b) discuss the notion that by understanding and addressing the patient's unmet health needs we can improve "caring services" and subsequently improve a patient's quality of life. They acknowledge that health needs are a complex concept with much variability (Asadi-Lari & Gray 2005). A health needs assessment questionnaire (Nottingham Health Needs Assessment – NHNA) was applied to cardiovascular chronic disease research in an effort to identify health care needs of individuals in a local area and subsequently allocate resources appropriately (Asadi-Lari, Packham, & Gray, 2005). Results indicated that the NHNA instrument appears to be a reliable means of identifying patient's needs, which in turn can affect how services are directed. The potential may exist to create a measure that would address the needs of those with an osteoporotic vertebral fracture.

A needs assessment questionnaire was utilized to determine whether or not information provided though an Arthritis clinic was of good quality (Adab et al., 2004). Asadi-Lari et al., (2003a) addressed the question of whether quality of life measurement was a proxy for health needs assessment in patients with coronary artery disease. Results suggested that health related quality of life tools appear to be a reasonable proxy for health care needs, in a population of patients with coronary artery disease. These research studies suggest that exploring health needs through a questionnaire is possible. At this time there is a lack of a validated method of conducting a needs assessment in the field of osteoporosis using a standardized questionnaire and more research is required in this area. In order to explore the patient's health needs a qualitative approach is required as a first step in the creation of a health needs assessment questionnaire specific to osteoporotic vertebral fractures.

As described below, few studies have explored the patient perspective related to determining programs and services in the community that might be beneficial to improving the quality of life of people with osteoporosis. The adequacy of current programs and services and how they relate to the needs of patients living with osteoporosis requires further exploration.

Several studies focused on knowledge and beliefs of patients with osteoporosis (Ribero, Blakeley, & Laryea, 2000; Jachna & Forbes-Thompson, 2005). Ribeiro et al. (2000) investigated patients' knowledge and beliefs about osteoporosis and concluded that women had little knowledge of osteoporosis and were receiving inadequate osteoporosis information to manage the disease. Jachna and Forbes-Thompson (2005) researched health beliefs of patients with respect to barriers and benefits of treatment. They concluded that limited knowledge of osteoporosis and lack of perceived risk of osteoporosis fractures were reasons for limited interest in osteoporosis management.

Jensen and Harder (2004) used a qualitative grounded theory approach to explore the female patient's osteoporotic pain experience and to investigate the potential of a structured Osteoporotic Pain Program to reduce pain and increase quality of life.

This study used semi-structured interviews to explore the meaning of the pain program for women. They found that by increasing the patient's self-efficacy in coping with pain the pain intensity appeared to decrease.

Although there are questionnaires that address beliefs and knowledge (Cadarette, Gignac, Beaton, Jaglal, & Hawker, 2007; Osteoporosis Quality of Life Study Group 1997) and quality of life, no questionnaires that address needs could be found. As a result, in order to explore the needs of those living with osteoporosis an approach that identifies needs is required. A qualitative study that focuses on the individual's needs seems to be the most appropriate method to study this phenomenon. Explicit focus on information, programs, and services would inform service providers about adequate programming and appropriate allocation of funding.

Richard Hovey's (2006) work on "What does it Mean to Live with Osteoporosis?" focused on the meaning of living with a chronic health condition, specifically osteoporosis. This qualitative study included 12 individuals who were interviewed at length regarding their perspective on learning they had a chronic illness and their experiences living with osteoporosis. Study recommendations included the need for information and education, and better physician-patient dialogue (Hovey, 2006).

The current research study will further explore this concept. It will expand on the lived experience of women diagnosed with osteoporotic vertebral fractures to identify what information, programs and services the women need in order to better manage their condition. The results of this study will inform Osteoporosis Canada and the Ontario Osteoporosis Strategy.

2.1.4 Purpose and Research Question

The purpose of this study is to explore the need for information, programs, and services of women living with osteoporotic vertebral fractures in the community. The research objectives of this study are:

1. To explore the needs of women with osteoporotic vertebral fractures living independently in the community.
2. To conduct an environmental scan of information, programs, and services related to osteoporosis currently available in the London area.
3. To identify gaps in information, programs, and services in the London area related to the management of osteoporosis, and in particular osteoporotic vertebral fractures.
4. The results of this study will be reviewed to determine the potential to inform the creation of a Needs Assessment questionnaire specific to osteoporotic vertebral fractures.

CHAPTER 3

METHODOLOGY

3.0 Ontological and Epistemological Assumptions

An interpretivist paradigm was selected as the worldview for this research project. It recognizes that there are multiple meanings, subjective realities, with social and historical influences (Guba & Lincoln, 1994; Ponterotto, 2005). The ontology of this approach reflects a relativist position that assumes the nature of reality is both singular and multiple and that a complex interaction of the two is needed to construct a reality (Guba & Lincoln, 1994). It is through the interaction between the researcher and participant that meaning is brought forth through dialogue and reflection (Ponterotto, 2005).

With regard to epistemology, this study reflects the view that supports a relationship with the study participants where the research participants are a direct part of knowledge creation through engaging them in dialogue and not simply their answers on a survey (Finlay & Ballinger, 2006). An interpretivist paradigm assumes that reality is socially constructed and that interaction between researcher and participant is necessary to tap into the lived experience of the participant (Ponterotto, 2005). In this study, the researcher requires a relationship with the study participants in order to explore their experiences, uncover meaning, and needs in order to best answer the research question about their need for information, programs and services.

3.1 Research Design

Phenomenology is used for a number of reasons including to uncover the deeper meaning of human experience, and to study a phenomena where there is little known about the phenomena (Starks & Brown-Trinidad, 2007).

Within phenomenology, there is a traditional philosophical approach reflected in the works of Husserl, Heidegger, Merleau-Ponty, and Gadamer (Dowling, 2007) and a more contemporary phenomenological approach, also called new phenomenology, scientific phenomenology or American phenomenology, reflected in the work of Max van Manen and Amedeo Giorgi (Dowling, 2007). Traditional phenomenology is concerned with discovering the essence of a phenomenon through the individual experience. This process includes immersion in the data over a considerable period of time (Wilding & Whiteford, 2005). American phenomenology concerns itself more with understanding the reality of the individual's experience of the phenomenon compared to traditional phenomenology that is more concerned with the essence of the phenomenon (Dowling, 2007). The research questions of this study are not concerned with what is the essence of a vertebral fracture (traditional phenomenology), rather with what is the experience of a person with a vertebral fracture (American phenomenology). It is important to note then that an American phenomenological approach is not used for the purpose of philosophical expression but for scientific research purpose (Dowling, 2007).In American and new phenomenology, researchers have used focus groups as far back as the 1980's. Spiegelberg (1982) outlined a procedure for what was termed at the time "group phenomenology" within the framework of American phenomenology. Benner (1984) used focus groups within a American phenomenology approach. The key to using focus groups was to ensure the research question was appropriate for the type of phenomenology employed namely American phenomenology. Giorgi (1985) argues that the researcher must make their position clear with respect to the type of phenomenology (Philosophical vs. American) used in order to ensure interpretations are within the scope of that approach.

In the fields of nursing and health sciences, researchers have used focus groups within an American phenomenological approach in order to explore the experiences of health care professionals and patients within the health care system (Robley, Farnsworth, Flynn, & Horne, 2004; Bush, Collings, Tamasese, & Waldegrave, 2005; Alexis, Vydelingum, & Robbins, 2007; Brunton, 2007; Hov, Hedelin, & Athlin, 2007; Plager & Conger, 2007; Charalambous, Papadopoulos & Beadsmoore, 2008; Ranse & Arbon, 2008). The use of focus groups provided not only the individual experience but also the collective experience of the focus group.

Focus groups as part of a phenomenological methodology can bring a greater understanding to the phenomena being investigated (Bradbury-Jones, Sambrook, & Irvine, 2009). Giorgi (1985) also talks about the notion of using new phenomenology as ‘inspiration’ to further qualitative research and evolve the research process. It would seem that over time the practical use of focus groups has merged with the goal of phenomenology. In terms of co-construction of knowledge, which is central to a interpretivist approach, when using a group interview format versus an individual interview format, it is important that the moderator is skilled and able to allow all participants to tell of their experiences of need in order to get a complete picture of the experience from the participant and not bias the group interview with their assumptions.

The method of data collection selected for this research study is that of focus groups. This choice requires some explanation. Focus groups are a “research technique that collects data through group interaction on a topic determined by the researcher” (Morgan 2004, p. 263). Focus groups were chosen because they can provide the perspective of the individual, build on the information presented by one person and understand how others in the group collectively view that information. Focus groups add an extra element of whether participants concur with information presented. Such information would not be available though individual interviews (Krueger & Casey, 2000). Focus groups not only elicit the experience of the individual but also build on the experiences of others who have encountered the same phenomenon. In this study participants were able to share their lived experiences with osteoporotic vertebral fractures with others and find commonalities and differences among their experiences, all of which added to an understanding of the phenomena.

3.2 Methods

3.2.1 Setting

This research project was conducted with the help of the London Regional Osteoporosis Clinic (LROC), operated by St. Joseph’s Health Care London located in London, Ontario. The LROC is a multidisciplinary team of clinicians who provide services aimed at the prevention, optimal management and rehabilitation of osteoporosis for clients in London and the surrounding 10 counties. The LROC was chosen as a partner because they serve patients with serious consequences of osteoporosis (fractures) who likely have the greatest need for information, programs and services. The medical director and registered nurse were the primary contacts at the clinic and the Registered

Nurse was involved in patient recruitment. Three focus groups were conducted, two were held at St. Joseph's Health Care London and one focus group was held in Mitchell, Ontario, a rural community located 45 minutes north of London. A rural focus group was included in order to capture diversity of experiences and needs of women living with osteoporotic vertebral fractures in the region.

3.2.2 Participants

The LROP treats patients referred by a family physician or specialist physician for management of osteoporosis. Some LROP patients may have had difficulty with drug treatment and require treatment by a specialist. Other LROP patients will have sustained one or more fractures of hip, spine, or wrist related to osteoporosis.

Participants were purposefully recruited to satisfy the following inclusion criteria: diagnosis of osteoporosis as indicated by referral to the regional osteoporosis program, living independently in the community (with or without support), previous vertebral fracture, age range from 55-90, residing in London or surrounding area (both urban and rural). Exclusion criteria included: acute medical conditions, living in long-term care, diagnosis of cognitive impairment, and not able to speak English. Participants were screened by the staff nurse at the LROP for cognitive impairment and excluded if they were deemed cognitively impaired.

Patients residing in long-term care were not included as their environments are more controlled than someone living independently in the community and as a result have less need for community based programs. Men were not included as research studies about osteoporosis in men are few and their need for information, program, and services may be substantially different than women. By focusing on women there is the potential for greater impact on information, programs, and services. The majority of research on osteoporosis, quality of life and needs have been with women. Additionally, the incidence of osteoporosis is greater in women than men (Josse & Brown 2002).

Participants in this study were nine women who lived independently in the community. All had been diagnosed with osteoporosis and had sustained a vertebral fracture in the past five years. Participants were recruited through information letters (Appendix B) that were made available at the LROP, information provided by the LROP staff nurse and posters posted through the LROP. If participants indicated interest, their name was communicated by LROP staff to the researcher for follow up and registration in the study. A consent (Appendix C) form was signed at the time of the focus group. Ethics approval for this research project was obtained from the University of Western Ontario research ethics board.

3.2.3 Demographic Questionnaire

The demographic questionnaire (Appendix D) was administered prior to the start of each focus group session. There were three parts to the questionnaire. Part A included information about gender, age, education, income, marital status, family support, caregiver status, support systems in place and place of residence. Part B gathered information regarding osteoporosis diagnosis date, vertebral fracture history, and Bone Mineral Density test score. Part C gathered information regarding falls, fractures (other than vertebral) and mobility aides utilized. An open ended question "What programs or services would you like to see in the community to help you manage your osteoporotic vertebral fracture?" was included to elicit specific feedback about programs and services participants would like to see in the community.

3.2.4 Focus Groups Protocol

In order to develop the appropriate focus group questions it was important to speak with women who had sustained osteoporotic vertebral fractures in advance of this study. A brief pilot project was conducted to obtain the input from two patients who had sustained an osteoporotic vertebral fracture. Two patients were identified by the staff nurse at the LROP who were then interviewed by the researcher and asked to provide testimony on what needs to be known about quality of life, osteoporosis management, and patient's needs from a patient perspective. Interviews were conducted at participant's homes for approximately one hour. Interviews were audio-taped and a consent form was signed. Responses from the two patients were analyzed using content analysis common themes were identified. They included need for pain control, difficulty in coping with changes of body shape, diminished ability to engage in leisure activities, and inability to perform activities of daily living. Results of the pilot interviews informed formulation of focus group questions.

The focus group followed the format described by Richard A. Krueger (2000), which employs the use of a moderator and assistant to facilitate the focus group. The role of the moderator was to arrange the room, arrange for refreshments, welcome participants, review the focus group topic, establish an open and friendly atmosphere, establish group communication guidelines, and to ensure protocol was followed yet allow for participant discussion. The role of the assistant was to ensure that digital audio recorders were properly functioning, to take written notes about discussed themes, to collect forms and keep time. Major themes discussed by the participants in each focus group were reviewed and addressed in subsequent focus groups.

At the beginning of the data collection session, the letter of information was reviewed with the participants and their questions were answered. Written consent was obtained and the demographic questionnaire was completed by all. Then the moderator asked questions and facilitated the focus group discussion. Each focus group session lasted between 60-90 minutes. Transportation costs to the focus group location were covered by the researcher.

The focus groups sessions were comprised of three components. See Appendix E for the complete focus group protocol. Part A related to questions about the effect of osteoporotic vertebral fractures on the participants life and associated challenges. Part B focused on information resources and Part C focused on programs and services.

3.2.5 Environmental Scan

An environmental scan is a review of information, data, and services in an area and is used by organizations as a starting point to assess a current situation in order to strategically plan for services and allocate resources (Choo, 2001). An environmental scan can be brief, high level or more detailed depending on the purpose. In this project, an environmental scan review was conducted to identify information, programs, and services currently available in London dedicated to supporting individuals with osteoporotic vertebral fractures.

The environmental scan included a review of services offered in the areas of physical activity, falls prevention, nutrition, medication, and seniors' programs that could act as a resource for individuals with osteoporotic vertebral fractures. The researcher contacted community centers and health care professionals who could act as a resource to individuals with osteoporotic vertebral fractures. These resources included pharmacists, dietitians, physiotherapists, nurses, physicians, and community organizations. An on-line search of services included Healthline (www.healthline.ca) – a site supported by the local Community Care Access Centre, to obtain a listing of local health services.

3.3 Data Analysis

3.3.1 Demographic form

Content analysis was used to analyze the open ended question. The results were reported in narrative format. The closed ended questions were analyzed by frequency and mean. The results were also reported in a narrative format.

3.3.2 Focus Group Data Analysis Process

The data analysis of the focus groups discussions followed protocol outlined by Giorgi (1985). This process involved reading and re-reading the transcripts to gain an understanding of the participants' experience with osteoporotic vertebral fractures and their needs. The transcripts were then coded line by line to identify smaller pieces of meaning. Codes were then grouped by topic and importance. The final step involved generating themes and reviewing the transcripts again to ensure that the interpretation fits the session as a whole. Giorgi does not support the re-interviewing of participants after data collection to review information gathered based on the assertion that the interviewer is the researcher not the participant (Giorgi 1985) and interpretation is based on the researcher's methodology, as a result the transcripts were not returned to the participants for their feedback. Strategies to ensure high quality of research will be discussed below.

3.3.3 Focus Group Transcription

After each focus group, the audio-recording was transcribed verbatim. Each transcript was then reviewed and compared to the audio-recording to ensure correctness. Any changes required were made and the transcripts were imported into NVivo 8 (Nvivo 8, 2008) for coding and analysis.

3.3.4 Coding

The printed transcripts were used for development of codes for line by line coding. The author and two experienced qualitative researchers independently read one focus group transcript and developed a draft list of codes. The group then came together and discussed the potential codes until consensus was reached and final coding scheme generated. The author then coded the remaining transcripts. Upon completion of coding of all transcripts, the grouping of codes into themes was discussed by the group and decided by consensus. Identified needs are reported in the Results section. Excerpts and quotations from transcripts are provided to support interpretation of findings.

Within American phenomenology, the practice of "bracketing" (the putting aside of one's own assumptions) is slightly different than philosophical phenomenology (Dowling, 2007). Giorgi (2000) suggests bracketing should occur only during data analysis and not during data collection, as during data collection the researcher would want to establish rapport with the participant. In this research study the researcher was open about knowledge brought to this research study and how it could have affected interpretation. During data analysis it was particularly important to bracket the author's knowledge/beliefs and let the experiences of the participants come through. This process was made easier by having multiple researchers read the transcripts, provide input, and determine initial codes. By doing this the author reduced the potential of influencing the codes with her own assumptions.

The number of focus groups was limited in part by difficulty with recruitment. After each focus group, the audio-tapes were reviewed as well as notes taken by the focus group assistant. By the end of the third focus group there were no new topics that emerged. As a result, the point of saturation was achieved.

3.3.5 Environmental Scan

The information collected in the environmental scan was obtained through contacting local resources via telephone and email about information, programs and services related to osteoporotic vertebral fractures and osteoporosis. The scan included feedback from physical activity centres, fitness centres, senior's centers, 3rd Age Outreach (Parkwood hospital), pharmacies, and Osteoporosis Canada. While the London Regional Osteoporosis Clinic services all people from south western Ontario, the scan of information, programs, and services currently available was limited to a narrower geographic region, specifically within the city of London.

3.4 Criteria for Evaluating Qualitative Research

3.4.1 Quality Considerations – Qualitative Research

Quality considerations will encompass two sections, quality considerations for qualitative research in general and additional quality considerations when using a phenomenological approach.

Ballinger (2006) outlines four general criteria to assess a qualitative study: coherence, systematic and careful research conduct (transparency), convincing and relevant interpretation, and role of the researcher. Coherence addresses how the research project fits together as a whole. This research project aims to understand and interpret the experience of women living with osteoporotic vertebral fractures through a lens that focuses on their need for information, programs, and services by engaging women to share their experiences and their insights into what would assist them in living with an osteoporotic vertebral fracture. The interpretivist worldview fits with the methodology (phenomenology) in that this seeks to construct knowledge with participants in order to tap into their lived experience and interpret this regarding needs. Through the use of focus groups one may be able to tap into the "taken for granted' by having women confirm or disagree with other experiences (Dowling, 2007). With regard to knowledge claims this study aims to understand the needs of women with osteoporotic vertebral fractures in this research study and makes no comment on the transferability of the results to women outside this study. With respect to a systematic approach, the use of new phenomenology supports a scientific approach to data collection and analysis including the use of criteria laid out by van Manen and Giorgi (Dowling, 2007). This study followed the steps outlined by these researchers in order to appropriately collect data and make interpretations. The criterion of "convincing and relevant interpretation" includes ensuring the use of multiple excerpts from the analysis and in-depth exploration of the participant's experience. This criterion requires explanation in this study due to the use of focus groups as method. In interviews one gets a participant's view of their experience however, while in focus groups participants a can see how others experience the phenomenon and the researcher can then see if that is true for each individual. It adds an aspect of further contemplation which participant's can then either concur or not based on their own experience. Focus groups can add richness to the data and to the experience of the participants and discuss things that one person may not have considered during an individual interview. As a result, you still tap into the individual experience but also the experience of the group and whether or not that experience rings true for the individual.

The criterion of 'role of the researcher' within new phenomenology is different than with traditional philosophical phenomenology. In new phenomenology the researcher does not always practice "bracketing" and assumes that one's own assumptions may affect the interaction with research participants (Dowling, 2007), however in this case it was important in the data analysis phase to bracket my own assumptions. It is for this reason that the researcher must reflect on this and discuss how their views may or may not impact on data collection, analysis and interpretation.

This researcher has an employment background in the field of osteoporosis and comes with some preconceived ideas about what patients might need. As a result the researcher had to set aside her own knowledge, beliefs and assumptions to listen to patients in order to let their true experiences emerge. The researcher had to consistently remind herself not to make assumptions that might influence the data but rather let the stories and experiences emerge through the flow of the focus group discussions. Specific questions about osteoporosis were answered at the conclusion of the focus groups.

By practicing reflexivity, through keeping a journal, field notes, and discussion with those involved with the research project, the researcher can be aware of how this may affect research outcomes and be transparent with regard to knowledge claims. Reflexivity is defined by Mason (1996) as research that:

> "Means that the researcher should constantly take stock of their actions and their role in the research process and subject these to the same critical scrutiny as the rest of their data." (pg. 6)

Reflexivity was practiced in this study through continually looking at my own assumptions and the experiences of the participants and trying to step back from my own assumptions during the data analysis phase of this project. Through working with a more experienced researcher my assumptions were questioned and thus ensured that the participants' voice was heard.

3.4.2 Quality Considerations – Phenomenology

Criteria specific to phenomenology include the concept of lived thoroughness/resonance, evocation/vividness, epiphany, and incorporation of philosophical framework (Wilding and Whiteford, 2005). Lived thoroughness/resonance is the concept where the reader can relate to the text and the experience of the participants. It is hoped that by reading the first section of the findings section of this thesis that readers get an understanding of the participants experience and that it makes sense to them. Evocation and vividness refers to the reader's reaction when they read the text. Text that is vivid should create an emotional response when read. As a researcher listening to the women's experience with osteoporotic vertebral fractures and their frustrations with their health care professionals one has a clearer understanding of their experiences. Epiphany relates to the readers reaction to the text. For this researcher, there were several quotes from participants where their lived experiences became clearer and understood in a different way, which makes me aware that I am open to seeing their experiences not clouded by my own preconceptions.

3.4.3 Knowledge Translation

Apart from determining patterns and common themes about needs of people with osteoporotic vertebral fractures, findings from this study will inform future health promotion and service delivery through the Osteoporosis Canada and the Ontario Osteoporosis Strategy. This study will also provide the groundwork for development of a larger provincial based needs assessment project that will be conducted by Osteoporosis Canada and the Ontario Osteoporosis Strategy. Results of this study will be presented to Senior Administration of Osteoporosis Canada and the Ontario Ministry of Health and Long-Term Care.

CHAPTER 4

RESULTS

The findings of this study form a framework that outlines how the participants view the experiences of living with an osteoporotic vertebral fracture. Findings and Interpretation are divided into three sections. The first section describes the demographic characteristics of the study group based on the demographic questionnaire. The second section presents the focus group results. Three main themes were identified and within these several sub-themes. The third section describes the results of an environmental scan of local programs and services related to osteoporosis in the London area.

4.0 Sample characteristics

A demographic questionnaire was completed by all focus group participants. There were three sections in the demographic questionnaire: Personal Information, Bone Health, and Mobility. The average age of the nine participants was 78.2 years with a range of 58 years to 88 years of age. All of the women came to the London Regional Osteoporosis Program for treatment. All participants were retired. Three of the women had to retire due to sustaining osteoporotic vertebral fractures. In terms of education four had a high school diploma and five had a post-secondary education. With regard to marital status two were single, three were widowed, two were divorced, and two were married. None of the participants were the primary caregiver for someone else. Five participants received care services in their home provided by an outside agency. Three received personal care and homemaking and one received only homemaking services. Three resided in an apartment, two resided in a single family home, three lived in a condominium, and one lived in an assisted living facility. One participant had an income level of < $10,000/year, two had an income level of between $10,000 and $25,000/year, three had an income level of between $25,000 and $50,000/year, and two had an income level > $50,000/year. One participant did not complete this section.

The second part of the questionnaire gathered data about bone health. Participants were diagnosed with osteoporosis between 4 and 17 years ago, seven had a history of multiple vertebral fractures and two had only one vertebral fracture. None of the participants knew their BMD score.

The third part of the questionnaire contained open ended questions about mobility including falls, broken bones, and assistive devices used. Of the nine participants, two had fallen once in the past year, and seven had previous fragility fractures other than their vertebral fracture. Seven participants were afraid to fall and the following reasons were listed: their balance was not reliable, they might break something, and that their bones were not strong. Those who indicated they were not afraid of falling indicated it was because they were cautious and because of this felt they would not fall.

The last question of the demographic questionnaire asked: "What programs or services would you like to see in the community to help you manage your osteoporotic vertebral fracture?"

Participants advised they wanted more public education lectures about the prevention of osteoporosis including information about calcium, vitamin D and diet. They also wanted more in-depth education about osteoporosis medications, side effects, pain medication, and alternative methods to control pain. They wanted their general practitioners to provide more knowledge about how to manage a vertebral fracture, and to explain test results better, particularly BMD results and x-rays. Participants wanted the health care professionals they encountered, such as physicians and physiotherapists, to be knowledgeable about osteoporosis. One participant was concerned that a physiotherapist without the appropriate training regarding osteoporosis and physical activity would make the participant's condition worse. Participants wanted more information about assistive devices, where to access them, and how to pay for them. Mentioned assistive devices included a bedrail for turning over at night, special seating for use in the car or while at a computer, and the use of a medical alert bracelet to let someone know in an emergency that they have osteoporosis and a vertebral fracture. Massage therapy, heat therapy, and nerve stimulation were indicated as means of pain control that they wanted to learn more about. They wanted more support services in the home, more help from clothing stores about what to wear, such as the best type of bra to minimize discomfort around the rib cage and availability of support vests. Participants wanted exercise programs specific to osteoporosis including specifics such as how to use weights and how to structure a walking program. They also wanted information about falls, preventing falls, and how balance exercise program may help with preventing falls.

4.1 Results of Focus Group Discussions

There were three main themes that emerged in the participant's description of the experience of living with an osteoporotic vertebral fracture:

1. Journey to diagnosis
2. Learning about the condition
3. Adapting to the condition

The following model outlines a theoretical framework of the experiences with osteoporotic vertebral fractures.

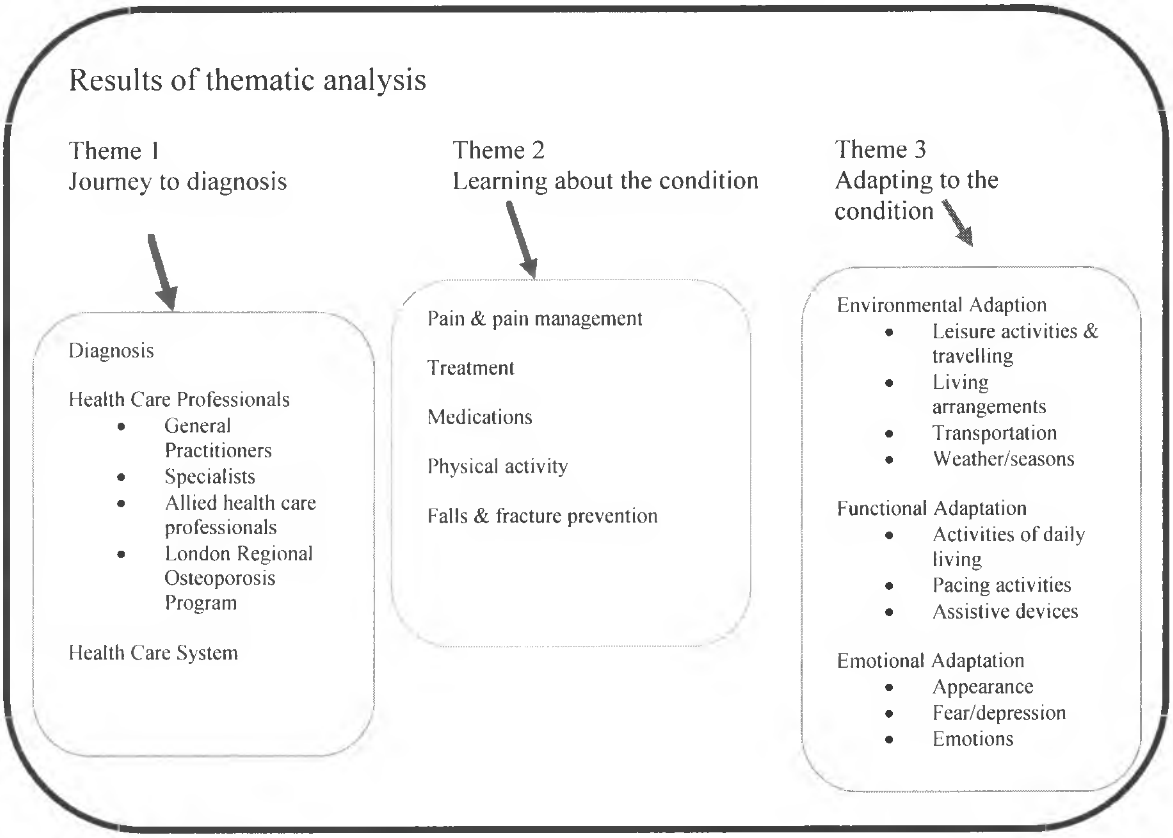

Figure 1. Framework – Experience of an osteoporotic vertebral fracture with respect to need for information, programs & services

4.2 Theme 1 – Journey to diagnosis

The theme *Journey to diagnosis* included three distinct but related sub themes *diagnosis, health care professionals* and *health care system.*

4.2.1 Diagnosis

When talking about *diagnosis* participants shared different experiences about their journey to a diagnosis of osteoporosis and a diagnosis of an osteoporotic vertebral fracture. There were several paths the participants experienced on their journey, some were diagnosed because of back pain that resulted in an x-ray, some were diagnosed because of a fall and fracture, and some were diagnosed after a Bone Mineral Density test. Some, despite an earlier diagnosis of osteoporosis, due to a lack of proper management of the disease, went on to sustain vertebral fractures. There were common experiences of a delay in diagnosis and misdiagnosis. This delay often led to falls and fractures that eventually led to diagnosis of an osteoporotic vertebral fracture.

Mary's story (focus group one – FG1) highlights a typical experience in the journey to a diagnosis of osteoporosis and vertebral fracture. It demonstrates the delay in diagnosis, the fracture, and finally referral to the London Regional Osteoporosis Clinic. This case represents many of the commonalities in almost every participant's road to osteoporosis diagnosis.

> "No, you see, I wasn't diagnosed with osteopenia. It was in 1991 that he [family physician] said I had osteoporosis and he put me on medication. I tried it for three months but my stomach wouldn't tolerate it. So he said: "Go back to your vitamin D and your calcium". Nothing happened. A year later, I was in such pain I couldn't drive myself to the doctor and my daughter came down and took me. He said: "Go home, put hot water and put heat on it. I'm putting you on morphine". And this is it. I said, "I'm sick and tired of your hot pads and your cold pads." I said, "The least you can do is give me an x-ray." So he ordered an x-ray. That's

> when we found the compression fractures and he's [family physician] always sent me home. Then he gave me some Fosamax that had expired four months before. So anyway, finally, in June, prescription for Fosamax. But see, I really feel I didn't get any treatment during those two years; no bone doctor, no nothing. So then, my doctor referred me to Dr. ______ [specialist], and I've been seeing Dr. ______ [specialist] once a year ever since."

Many of the focus groups participants expressed commonalities in how they experienced their first osteoporotic vertebral fracture in terms of the process, the length of time, and challenges. What is notable was their long road to a diagnosis despite, in many cases, having sustained a prior fragility fracture. Natalie (FG 3) experienced a fall and fragility fracture in her 50s, which is an indicator of osteoporosis, and yet was not investigated for osteoporosis.

> "I'm trying to think which, which came first, the, like I fell. Like so many people fracture the wrist and ankle. And at that time, I don't think I was referred to the clinic then, but a little later on, I was."

Joan's (FG 1) story of experiencing multiple fractures prior to a diagnosis of osteoporosis highlights the extended length of time it took to finally have a diagnosis of osteoporosis.

> "So I originally started with fractures of an ankle and also a toe, and that was in the '90's. And then I had vertebral compression fractures around, I saw Dr. _____ around '95. And then they started, I had the most of them thoracic ones and then lumbar, I had some lumbar vertebral fractures"

Joan's experience highlights how participants were diagnosed at different stages of the severity of the disease and how the consequences of a delay became more serious while patients were searching for answers. Participants wondered whether if they had been diagnosed earlier by their health care professionals, the pain and suffering they experienced might have been avoided. This was the case with Mary's experience:

> "And I didn't show it when I had my first bone density in '99, I had osteopenia. I wasn't diagnosed until two years later after I had [the second bone density]. And then he put me on treatment".

Participants, who had experienced previous fragility fractures but were not diagnosed, remarked that had they known about osteoporosis, they could have taken steps to prevent fractures. Doris (FG 2) shares her experience about experiencing a vertebral fracture while gardening. Gardening was an activity she and many other participants enjoyed prior to their fracture.

> "Yeah, I was, well, I think I was trimming, my hedges were like twelve feet high, and I was trimming, and the first I noticed that maybe something was wrong, I just didn't feel right lifting these ladders along the hedge. But I still went on and I finished the hedges and I was at the last flowerbed at the front lane on the ground trying to get it finished and that was that."

In Doris' case the delay in diagnosis came from both the patient and the physician. Doris' (FG 2) experience highlighted how participating in usual activities of daily living led to her fracture. She tried to handle the condition on her own, contributing to a delay in the diagnosis, but found her back very painful so she went to a physician. It was then that she learned about the fracture. Many of the participants had similar experiences.

> "And then talking about the back fractures, I was just sitting in the bath tub reaching down to turn something up and snap, you know how it happened. And I didn't go to the doctor with it. I just thought I pulled something and it was so horribly painful, as you say it is. And I lived with that for a while and after I went to the clinic, I was referred to the clinic, and they did the x-ray and they said, "Well, you had a fracture", you know."

There was at least one person in each focus group who felt they were misdiagnosed by a physician. Irene (FG 3) was advised she had osteoarthritis that caused the back pain when in fact the pain was due to a vertebral fracture.

> "Well, my initial fracture was in 2005. And I didn't know I had it at all until I'm in extreme pain and then I did this [broke the ankle]. My last bone density was two years ago and he [family physician] said, "You have osteoarthritis" He said, "That what's causing you all this back pain."

Joan (FG 1) had several medical conditions that contributed to her complex medical needs, contributing to difficulty in coming to a diagnosis and appropriate treatment.

> "So the next episode, really severe one, was last August. And I woke up and I was in, couldn't turn over and I was in real agony. I have screws in my back between L2 and L4. And the L2 and L4, I guess there'd been some, that was nine years ago I had this surgery but the compression fractures have occurred and they collapsed. So I had CT scans and x-rays to see them, what was happening."

While talking about their *journey to diagnosis* participants reflected on the information, programs and services they used and those they wanted to have had. Participants expressed a need for prevention information and indicated had they received it at an earlier stage of the disease they would have changed their lifestyle in order to prevent consecutive fractures. For example, many of the women engaged in activities they normally would do such as gardening. However, because they were unaware they had osteoporosis they did not take precautions in order to prevent a fracture. Mary (FG 1) summed up well the participants opinion regarding prevention information.

> "Knowing that they didn't start treating for osteopenia then I would have been more careful about getting enough Vitamin D and those things. And I would have tried to take better care of myself for facing the future, yes."

Mary further expressed the need for more education materials aimed at the general public and not health care professionals. Many women found information to be too clinical and not easily understood.

> "You know, sometimes we don't have any knowledge whatsoever and I did try the library to get a bit of knowledge. But most of it can be professional that goes in with, you know, right over your head if you don't understand what you're reading about."

Findings related to *journey to diagnosis* should be interpreted in historical context of when participants were diagnosed with the disease. According to the demographic information the length of time since diagnosis for this group of participants was 4-17 years ago, which means the diagnosis was made between 1992 and 2005. Over this period, the awareness about osteoporosis among health care professionals and the general public has improved. Patients diagnosed today may have a different experience with journey to diagnosis than the sample of participants in this study.

4.2.2 Health care professionals

During their journey to diagnosis, the participants encountered numerous health care professionals. Their experiences with health care professionals and the health care system affected their information seeking behaviour. Several sub-themes emerged including *general practitioners, specialists, allied health care professionals* and the *London Regional Osteoporosis Program.* Allied health care professionals included physiotherapists, pharmacists, and nurses. The greatest number of quotes (52) was coded under the general practitioner code. Health care professionals were either seen as a facilitator or barrier in the journey to a diagnosis of osteoporosis or treatment of an osteoporotic vertebral fracture.

4.2.2.1 General Practitioners

The discussion about general practitioners came up in each focus group and resulted in a passionate reaction from participants. There was consensus that participants felt like general practitioners were not a facilitator in the journey to diagnosis. Beth (FG 1) summed up the participant's thoughts about involvement of general practitioners.

"There are people who need help and aren't getting help."

One of the most significant issues was that general practitioners did not listen when women talked about their symptoms and health concerns. Mary's (FG 1) experience underlines the need for her general practitioner to be more familiar with her medical conditions in general.

> "My doctor, well I went for a year without a doctor, so I do have one now, but she won't listen. I tell her I have a bad reaction to acetaminophen, well don't I know that? Well I said: "I don't know why you don't know but I tell you every time". She just doesn't listen."

Many participants initially were not diagnosed or treated for osteoporosis until they had a fracture and sometimes well after the initial fracture. Mary (FG 1) did not receive a diagnosis until she had sustained multiple fractures, which is an extreme example of a delay in diagnosis. She felt that had she been diagnosed earlier she would not have had the difficulties that she has now.

> "Well, I didn't get the proper care from my doctor but, he's not practicing now, so he's not hurting anybody."

Participants talked about general practitioners who initially misdiagnosed their condition, and also gave them incorrect information. Both Betty and Doris (FG 2) had a particularly difficult journey to diagnosis and endured treatment and diagnostic procedures not related to osteoporosis before a correct diagnosis and treatment were received.

> "So that's when I went to the doctor [family physician] the next day and he said, "Maybe a chiropractor could help you with the back pain". " (Betty)

> "Well, he was the one who kept sending me down for enemas when I kept complaining, I was down three times. And, so then once they saw the fracture, then he booked me with Dr. ___ [specialist] right away." (Doris)

The participants talked about how physicians have the opportunity to provide them with information but that they did not take the time to do so. Overall, participants indicated dissatisfaction with their general practitioners. The delay in diagnosis was also attributed to the patient's own silence and the physician's prioritizing care of family members as in Irene's case (FG 3). For most participants it was not until they were seen by a specialist or referred to the London Regional Osteoporosis Clinic that their condition was diagnosed and treated.

> "My family doctor did apologize to me. He said that, you know, he should have been after me when I was in my 50's to take calcium so that I wouldn't get osteoporosis. But he was looking after my husband and my daughter who both needed care more than I did. And he didn't realize that I was going through the change and I didn't complain."

Despite a negative experience with her general practitioner Irene acknowledged that she did not complain about her concerns either. Shirley (FG 3) also acknowledged that she should have pursued better care and advocated more for herself.

> "And so, I mean, he didn't pay any attention to me, and he should have been telling me that I needed calcium to strengthen my bones so that I wouldn't get osteoporosis. And I knew this, you know. I knew I probably should take it but, and I knew that women got osteoporosis. But I thought, I'm healthy, I won't get it."

The major issues participants experienced with the general practitioners were: they did not listen, they did not do any diagnostics or treatments until a first and sometimes second fracture occurred, they were misdiagnosed, and they were not provided with prevention recommendations.

4.2.2.2 Specialists

Overall, the participants had a more positive experience with specialists and saw them as a facilitator in their journey to diagnosis. Specialists quickly recognized osteoporosis and in particular vertebral fractures. Specialists in this study included Oncologists, Rheumatologists, Endocrinologists and Geriatricians. Specialists subsequently made a referral for appropriate diagnosis and treatment. Both Mary and Beth (FG 1) had similar experiences with their specialists.

> "Now, from the specialists, I get more information from, say, Dr. _____ because he's knowledgeable and he knows what to ask." (Mary)

> "A year later, they put me on once a week [OP medication] and that ended up in colonoscopy because I bled so much. And I complained to my oncologist that I was sick and tired of taking dumb medications. He said, "Leave it with me I'll fix it for you." So she contacted Dr. _____ [specialist]." (Beth)

4.2.2.3 Allied health care professionals

Participant's experience with allied health care professionals such as physiotherapists, pharmacists, and nurses was generally more favourable. None of the participants mentioned occupational therapists, nurse specialists, or dieticians in any of the focus group discussions. Experiences with physiotherapists were mixed. Some participants found physiotherapists knowledgeable while others wanted physiotherapists to have more knowledge about osteoporosis and vertebral fractures. Joan (FG 1) had numerous co-morbidities and questioned the skills and knowledge of her physiotherapist.

> "But I think there is a lack of knowledge amongst the medical profession and physios because I had a physio who was treating me for other things; for my Meniere's and visual tracking, and she did some work with my joints. But I think she intensified my osteoporosis 'cause it was just after that, my joints fractured. And I think maybe they have to be aware and take better histories and know that that person has osteoporosis or not, on handling, you know somebody."

Beth (FG 1) however found the physiotherapist who acknowledged she did not have all the answers and would seek out other physiotherapists for more information.

> "And physiotherapist has, several times, gone to colleagues of hers that are therapists and said: "You know, what do you think? Can I use this on _____ [participant] or can I do this [therapies]? So she is really trying to find out what [are] the best things for what her patient needs."

Shirley (FG 3) found the physiotherapist helpful not only with her osteoporosis but back health in general.

> "I had some physiotherapy at the hospital. And the therapist was very, very good. So I said, "You know I have a back problem. What shall I do about it? She showed me some exercises to do. I joined the [fitness club] and I go at least four times a week."

Cost of the physiotherapy sessions and the transportation to treatments were barriers for using physiotherapy services. Irene (FG 3) had the physiotherapy costs covered but transportation was an issue for her.

> "It didn't cost [physiotherapy]. After my fractured hip, I had until January to July and I only took three treatments, because I pay $25.00 taxi to get there, and $25.00 taxi to get home. "

Several participants recognized the importance of physiotherapy so they came up with solutions to meet their financial and physical needs. Shirley (FG 3) attended physiotherapy for a short period of time and then followed the exercises prescribed at home rather than pay for the services of a physiotherapist.

> "I took three treatments and gathered all I could from her, and [I] do it myself."

Pharmacists were considered a good source of information but participants didn't always see them as the primary provider of print information. Participants tended to see their general practitioners in this role. Mary (FG 1) recommended approaching the pharmacist but she had difficulty with the content and interpretation of the information presented in pamphlets.

> "I find you have to approach the pharmacist you know. They give you a written thing, you know, with the side effects. But if you don't read it, and that then they scare you to death because there are so many things. It's always frightening."

Jess (FG 3) found her experience obtaining information through the pharmacist a good way to obtain reliable information.

> "Anytime I have a new prescription, they always take me aside and explain what it's all about. Very good."

Shirley (FG 3) spoke about reading pamphlets available in waiting rooms of the health care professionals. This seemed to be a common way for participants to access health information for prevention and management of medical conditions.

> "Quite often, when you go into the pharmacy or into a doctor's office or something like that, there will be pamphlets around and all the different things. Especially if I have to wait for a doctor, I'm always looking for these pamphlets. One of these could be useful to me".

4.2.2.4 London Regional Osteoporosis Program

The *London Regional Osteoporosis Program* (LROP) was for many participants the first place where they were treated for osteoporosis. Participants found this to be a positive experience. Natalie (FG 3) received more up to date information at the LROP than any other place.

> "And I've been kind of unhappy with his approach so I found another doctor and she recognized I had osteoporosis and referred me to the clinic [LROP] so that's where I'm getting results for I suppose seven, eight years. And that certainly is the place to be."

Betty (FG 2) expressed gratitude for receiving treatment through the LROP because her numerous fractures make her situation difficult.

> "Yeah, I think I'm still lucky to be able to, to get the [infusion] at [LROP].

In summary of this sub-theme participants found that general practitioners did not meet their needs in terms of diagnosis. Eventually some general practitioners were able to provide a diagnosis and provide treatment. However, often it was not until the participants were referred to the LROP that they were adequately treated. Specialists were often the catalyst to diagnosis and treatment. Allied health care professionals were seen as more helpful with resources and time available to spend with patients to provide education.

With regard to information, programs, and services related to health care professionals, participants expected their health care professionals to be constantly updated about treatment of osteoporosis. Joan (FG 1) had some suggestions about how to educate general practitioners to be more up to date about osteoporosis.

> "Yeah, continuing medical, they should have more on how to treat osteoporosis patients, and even have a panel with somebody on the panel who's got it and can field questions as well or ask."

Participants saw physician's offices and pharmacies as a good place to obtain information about osteoporosis and a good way for health professionals to disseminate information about osteoporosis. Joan (FG 1) found information in her specialist's office, however she thought that having the information available through her general practitioner would have been more beneficial.

> "And there should be more PR [public relations] about it. So that's where I got my information or pamphlets from her office. But really the doctor, my own doctor, I hate to say, didn't really help much."

4.2.3 Health Care System

This sub theme primarily included difficulties participants had either navigating through the health care system or barriers they encountered during their journey to diagnosis. Participants spent a long time discussing the health care system and were very passionate about the issues raised. There were over 30 quotes in the *health care system* sub-theme. They expressed frustration with a lack of time available for consultation with their physician, being charged extra for visits and notes, having multiple medical conditions and being allowed to discuss only one during a visit with the physician. This meant that patients had to come back another day which was inconvenient due to increased time, added cost for transportation and fatigue.

The participants recognized that as they age they may have more than one chronic condition that affects their well being. Beth (FG 1) summed up this experience with her family physician.

> "And when we go, I write little notes. He says, I can only look after one, five minutes, I can only look after one problem. You'll have to come and have another half hour. I get so frustrated by this because I have a complex system."

Mary (FG 1) concurred with Beth and suggested longer appointment times should be available for those with multiple medical conditions.

> "Yeah, I think they should allot half an hour for seeing you when they do, you know, when you go to see them instead of five to ten, eight minutes for each patient."

Additionally, Beth (FG 1) expressed a need for physicians to listen to their patients, be able to discuss more than one condition at a time, and a need for the health care system to accommodate the patient and not the physician.

> "For one thing only. So he'd already got prescriptions refilled and that's it. You have to come back tomorrow. You have to accommodate the doctor. And they still don't listen."

Despite their frustration Mary (FG 1) understood the pressures of the health care system and how chronic disease and multiple medical conditions were time consuming for the physician.

> "It's an aging population now, so they're getting inundated with chronic diseases."

Discussion also revealed that many general practitioners charged patients either a fee per medical note or yearly fees to cover additional medical services not covered by Ontario Health Insurance Plan.

> "Sometimes they charge a yearly rate, $120 and that covers everything." (Joan FG 1)

Both Beth and Joan (FG 1) incurred additional costs of administration fees from their physician's offices. Beth in particular complained that patients were not made aware of these fees prior to the visit.

> "And you should be warned [by the doctor's office] if you got to write a few more letters and not charge you $10 or $20 for each letter."

In summary, the participants expressed a need for a health care system that will be sensitive to and address their needs as an aging population. They wanted health care professionals to understand that they have complex medical problems with multiple co-morbidities. They had difficulty communicating their medical needs in short visits and complained of not being heard. The participants demonstrated health seeking behaviours yet were unable to receive the appropriate care. It was not until they had fractures and were referred to the LROC that they received adequate treatment.

4.2.4 Summary – Lived experiences related to the Journey to Diagnosis and need for Information, Programs, and Services

The theme *Journey to Diagnosis* identified a variety of information, programs, and services both used or desired by participants during this process. The participants primarily expressed a need to receive information on prevention of osteoporosis long before diagnosis or first osteoporotic vertebral fracture. The participants wanted their primary health care providers to be knowledgeable about osteoporosis and to provide a diagnosis in a timely manner. They want their general practitioners to listen and work together with them on a solution. Participants expressed a desire to have health care professionals engaged in continuing medical education programs in order to provide reliable diagnosis and treat their condition. In terms of appropriate locations to obtain information about osteoporosis, participants thought the offices of their general practitioners and specialists were a good place to provide written educational information about prevention.

The participants strongly expressed a need to have a health care system that allows more time at each visit with general practitioner to go over their multiple medical conditions and adequately address their complex medical needs. This opinion was not only related to osteoporosis and vertebral fractures but to a variety of their health care needs.

4.3 Theme 2 – Learning about the condition

This theme included how participants experienced the process of *learning about the condition* and how they gathered information about *pain and pain management*, *treatment, medication, physical activity*, and *falls & fracture prevention*. The women recounted their experiences in learning about osteoporosis and vertebral fractures.

4.3.1 Pain and Pain management

Pain and *pain management* was a sub theme that generated much discussion in all the focus groups. It was referenced 53 times in three focus groups. Participants had to learn to cope with the initial acute pain of a vertebral fracture. Subsequently, the women noted that even though their fracture healed they had to learn to cope with ongoing back pain as a result of postural changes in the spine. There were many facets to pain brought forth including the unexpected intensity of the pain that was described by Beth (FG 1) as she talks about the acute vertebral fracture.

"Hell. During the time, the feeling [was] sheer hell."

Joan (FG 1) acknowledged that the pain was significant and there was an underestimation of the pain level because of the vertebral fracture.

> "And I didn't realize what, well, I know bone pain because I've had two spinal surgeries and I thought a bus had run over the back of me when I came out from the aesthetic. But the bone, those were actually surgeries but when I had the vertebral fractures, compression fractures, I found equally the pain was, bone pain is really, really painful."

Pain tolerance level was a topic of discussion within the groups. There was agreement about how the women saw themselves as having a high pain tolerance, which helped them learn to cope with their pain. The women were stoic in their approach to coping with pain, which they learned to tolerate because they did not have many options for pain control presented to them. Beth's (FG 1) experience was typical in that she endured the pain because she did not feel there was much she could do about it.

> "Your pain tolerance is great. And me I was fascinated, it hurt like hell but I was still, you know, there. But I guess I just tolerate it. And the same with my back now, it's there and [there is] not much I can do about it. If it gets real bad, [I] lay down flat for ten minutes and see if it'll go away and then [I] get up and walk around."

The women took different approaches to cope with pain, some through medications and some through alternatives like rest and posture changes. The women agreed that learning to find ways to reduce pain was the goal. Beth and Mary (FG 1) were in agreement about the relief of having the pain subside.

> "Find the comfortable spot and sit there for a few minutes until it calms down" (Beth)

> "Then once you find it, you don't want to ever move, once you find that comfortable spot" (Mary)

The use of pain medication, difficulty coping with pain, lack of understanding of pain by health care professionals, and the need for better pain control were repeatedly expressed. Joan (FG 1) had back pain yet was wary of narcotics and the side effects.

> "Yes, well, I was put on Percocet and OxyContin because the pain was very severe."..... "I wanted to get off them 'cause my stomach got upset."

It was through the LROC that Beth (FG 1) found relief through medication prescribed through her specialist.

> "I try to get by and Dr. ____ [LROP] gave me something and you snort it up one nostril this morning then the other one tomorrow morning. That has really helped me get through the pain."

Joan (FG 1) was prescribed narcotics for pain control that she did not want to use because of perceived side effects.

> "So whichever [side] I lay on, on the back, I was uncomfortable. So it was the first time I was tried on narcotics and I would say to people, "If you can try and keep off them, do." Because of all the side effects of them and the constipation."

Through the process of dealing with pain the women learned how to cope with pain through traditional medical therapies (drug therapy) but wanted alternatives as well. Their treatment modalities included medications, physiotherapy, massage therapy, TENS machine, Deep Cool, alternating heat and cold, and back braces. Mary (FG 1) was typical in that she wanted alternatives to medication to alleviate pain.

> "Especially, at the start [of the pain]. And I still get some relief by rubbing my back with Deep Cool."

Participants wanted information about the best and safest methods of pain reduction. Beth (FG 1) expressed her desire for massage therapy and expressed her concern to make sure it is safe for someone with vertebral fractures.

> "And massage therapy too. I mean they have that in a lot of retirement homes but if it's done on somebody who has compression fractures and they do it too hard on, we're going to be in more trouble, I think."

Participants wanted information on both how to cope with the acute pain of the fracture and how to cope with subsequent chronic back pain. The women acknowledged that once the pain was under control, instead of modifying their activities, they engaged in activities they knew might exacerbate pain. Mary (FG 1) was honest in admitting this:

> "Don't ask me, I'm a bad role model. Once the pain was eased then I'd tend to do things I shouldn't like moving furniture."

4.3.2 Treatment

Treatment included experiences of learning how to adapt to treatment for osteoporotic vertebral fractures. Participants expressed a desire for treatment that was timely and appropriate. They wanted to ensure people with osteoporosis received treatment. Joan (FG 1) expressed her thoughts about the lack of treatment provided by the general practitioner and the need for patients to speak up for themselves.

> "I wasn't diagnosed until two years later after I had the second bone density. And then he put me on treatment. Too many people are not getting treated for osteoporosis and all I can tell is, "Have your family doctor refer you". I say Dr. _____ [LROP] because I know Dr. _____ [LROP] but I know there are other doctors and if she [friend] spoke up, they would get in with someone but they never seem to follow through on it. She [friend] would be amazed how many people are not receiving any treatment at all."

While learning about treatment for osteoporosis the women realized that lifestyle change is needed after a fracture that included other considerations such as proper nutrition, calcium, and vitamin D supplements. Natalie (FG 3) indicated she would have made some lifestyle changes to incorporate additional measure in order to treat her osteoporosis, had she known about them years prior to vertebral fractures.

> "Then I think he [general practitioner] told me there wasn't anything that he could do. It's too late to do the calcium and so on. It was only since I've been to London [LROP] that I've actually been treating my osteoporosis. He [general practitioner] even told me it was too late to start of calcium and vitamin D, so I put up with that for a long time."

4.3.3 Medications

Medication was a sub-theme under *learning about the condition*. The women described their reaction to medications used to treat osteoporosis and discussed the difficulty they had adapting to medications (bisphosphonates). There was consensus that the IV therapy Pamidronate they received through the LROP was treatment that worked well for them. Beth's (FG 1) was typical experience of difficulty the participants had in tolerating bisphosphonates.

> "Fosamax destroyed my stomach……. yeah, it's terrible stuff, I had to come off it. And even Actonel, I had to come off."

Rich discussion produced different aspects of medication use including difficulty taking it, side effects and the appreciation for the treatment participants were receiving through the LROP, which was not only effective but easier to tolerate. Betty (FG 2) received an IV infusion every 3 months.

> "I feel I am lucky to be getting Pamidronate."

Joan (FG 1) had concerns with medication she was prescribed for rheumatoid arthritis that was a risk factor for osteoporosis. She was one of the few who understood additional risk factors for fracture.

> "And that was the treatment then [for rheumatoid arthritis] and now I can't go off the Prednisone. So, I'm continually having it so I'm continually in fear of breaking my bones and being more fragile."

The women in general would have preferred not to take any medication at all due to the side effects. Beth (FG 1) expressed a need for information about medication options that did not have side effects.

> "Medication, is there something one can take that you don't tear your stomach apart?"

The cost of medications and coverage were brought up in discussion. Some medications were covered by the Ontario Drug Benefit while others were covered by a private plan. Natalie (FG 3) expressed her need for information about medications that are covered as this affects her ability to pay for treatment.

> "I'm with [drug company]........ it's surprising what they don't cover, when it comes down to it, they tell you this is such a good system but then when they want to use it, well, it doesn't cover that."

4.3.4 Physical Activity

Physical activity had several different meanings for the participants. Physical activity was included under *learning about the condition* as the participants spent considerable time finding the right type of physical activity and saw it as a significant part of managing their osteoporosis. Overall, physical activity had a high number of quotes (64). There was agreement in the focus groups about the value of participating in physical activity however, there were barriers to participation such as weather, transportation, and motivation. Some women expressed a need for finding a personal trainer to help with exercises specific to osteoporosis. The cost of physical activity programs was a concern. A physiotherapist or personal trainer (at an exercise facility) was helpful in constructing an exercise program however the additional cost of using this service was prohibitive. Finding information about the right type of exercise was also a concern. The women wanted to know what exercises they could do safely and what exercises were not safe for a person with osteoporotic vertebral fractures. Beth (FG 1) found it difficult to find this type of information.

> "I would ask her [physician]. She [physician] probably got fed up with me but I did get good knowledge about exercise. Should I be exercising and to what extent or what type of exercise, you know. And they do have groups, you see, they're vital."

Women had varying degrees of initiative and comfort in trying to develop the best type of physical activity program to accommodate their condition. Some were satisfied with "figuring it out" on their own while others wanted more direction from a physical activity professional. Physical activity was seen by participants as both participating in a formal exercise program and staying physical active in general. Natalie (FG 3) was able to create a program for herself.

> "Oh yes. Actually, I didn't go for osteoporosis [physiotherapy], I went for my hip at first. Then I developed a program because I'd been going to the Y [YMCA] for 25 years. Then I went to the [fitness club] because it's closer and I think their machines are better at the [fitness club] too. Figure out your own program, because they have pictures of back, front, whatever. And it's fun, at least [I]think it is. It's an addiction. If I don't do it I am very blue."

Discussion also focused around the difficulty women experienced with incorporating physical activity into their already limited ability to participate in activities of daily living. Participants knew physical activity was a significant part of managing osteoporosis and reducing their risk of further fractures so they wanted to engage in physical activity. Betty (FG 2) explained how she managed to successfully combine physical activity with activities of daily living into her routine.

> "But I didn't [exercise] today. If I'm going to do the washing and when I have a busy day I don't go. But I can do, I can do thirty minutes, twenty minutes is about right and I can go a mile and a half in twenty minutes. But I don't do it every day. And I don't do some of my other exercises as long as I should."

However, by participating in physical activity programs participants expended energy and sometimes were too tired to complete activities of daily living. They had to balance completion of household tasks with getting enough physical activity. Doris (FG 2) expressed how she learned to incorporate physical activity safely into her routine.

> "As far as the steps. I try and remember to do them, I have some exercises that I do for my bicycle, and actually I tried to incorporate a few of them every day, but if I'm going down the stairs I try and do that before I do it [exercises]. I find it easier going up than down the stairs."

Weather and the season affected whether or not participants were able to take part in physical activity programs. Beth (FG 1) expressed how the winter season prevented her from participating in physical activity.

> "I can only walk maybe one block at a time, you know. And, with the walker, it's better but, with winter, we have such a long winter, we get sort of stagnant. And then we stay in."

Betty (FG 2) preferred to walk outside. However, she recognized it was unsafe during the winter months and modified her program by using a treadmill indoors.

> "I don't walk out on the road anymore. I used to walk the side road, but this winter, I haven't been out at all, I've been using the treadmill."

Because of the challenges of the winter season, participants expressed a need for physical activity programs that were flexible and could be adapted to the changing seasons.

4.3.5 Falls and fracture prevention

Falls and fractures were seen as part of *learning about the condition* in that the women became aware of the importance of falls prevention in order to avoid either another fall and possible fracture. Most of the women had previous falls that resulted in a mild trauma or fragility fracture other than vertebral. Through learning about falls and falls prevention Betty (FG 2) became aware of how to safely manage activities of daily living in the home and avoid falls by safely using assistive devices such as step stools:

> "But yeah, I think you'd be very careful what you're taking off the top shelf with it [step stool], because [the stool] is not all that substantial [and I might fall]."

There were also some innovative ways to cope with the consequences of falls. The following quote from Joan (FG 1) illustrates a novel approach to learning how to cope with injury as a result of a fall:

> "One thing I hadn't thought about but I wear an allergy bracelet, because I have Prednisone but I put osteoporosis on it now. Because if I fell at least they'll have some idea that I might be on special drugs relating to it, but also, you know, I might have a compression fracture rather than a real fracture. So, I'd advise people to be made aware of the allergy bracelet."

4.3.6 Summary – Lived experiences related to learning about the condition and need for Information, Programs, and Services

Within the theme *learning about the condition* participants had to learn to accept and cope with the introduction of treatment through medication, physical activity programs, and falls/fracture reduction strategies to their lives. The women were hesitant to take additional medication and were concerned about potential side effects. The most relevant information need for participants was information about medications (how to take them properly, side effects, cost, coverage by health plans). The women wanted to ensure that the information they obtained was correct and supported by a credible source. The majority of women viewed their general practitioner as the most credible source of information however acknowledged that pharmacists and physiotherapists could be a good source as well. As the participants learned about the consequences of osteoporosis through sustaining a vertebral fracture they had to learn about falls and further fracture prevention which resulted in lifestyle changes.

Through *learning about the condition* there were different experiences with information, programs, and services. Participants used pamphlets obtained from physician's offices, books from the library, web-based information and Osteoporosis Canada's website. Participants indicated they wanted more print information to be available from physician's offices. They wanted print information to be easy to understand for the average person and credible. They wanted print information about medications, pain management, and physical activity programs. Mary (FG 1) highlighted how she found osteoporosis educational material too clinical.

"Page after page after page with absolutely no information for a lay person"

The sources of information included physicians (general practitioners, specialists, and nurses at physician's offices), pharmacists, physiotherapists, internet websites, and magazines.

Most of the women indicated they utilized programs and services such as physical activity programs at the Canadian Centre for Activity and Aging, and private fitness clubs. There was a lack of information about how to identify which fitness facility or exercise professional was experienced with osteoporosis-specific exercise. With regard to preferred programs and services several opinions were expressed. Participants learned about the importance of participating in physical activity programs, which they all agreed was something they should do. They expressed a need for a physical activity program that was flexible to meet their lifestyles. Factors that were a barrier for attending physical activity programs were cost, weather, transportation, physical energy costs of engaging in exercise, and concern about the qualifications of the instructor. The women indicated that they wanted pain management programs to help them to cope with the acute pain of a vertebral fracture and also the chronic pain as a result of the vertebral fractures and changes in the spine.

4.4 Theme 3 – Adapting to the condition

Adapting to the condition contained three sub-themes, *environmental, functional*, and *emotional* adaptation. *Environmental adaptation* included *leisure activities and traveling, living arrangements, transportation and weather/seasons.* The women had to learn to adapt to the existing environment because of their condition, both inside and outside the home. The sub theme of *functional adaptation* included *adapting to activities of daily living, pacing activities, and using assistive devices* both inside and outside the home. The last sub theme was *emotional adaptation* and involved adapting to body changes such as *appearance, fear, and emotions* such as depression. This theme generated a significant amount of discussion among participants who indicated a high demand for information, programs, and services in learning to adapt to their condition.

4.4.1 Environmental Adaptation

4.4.1.1 Leisure Activities and Travelling

Participants discussed how an osteoporotic vertebral fracture had affected their leisure activities and the need for assistance in adapting them. Leisure activities that were too physically demanding, such as gardening and sports, had to be eliminated. The women found they were more sedentary as a result. Joan (FG 1) found herself engaging in less physically demanding activities such as walking rather than previously enjoyed sports.

> "I played a lot of sports and now I watch a lot of sports, particularly, winter ice skating and that sort of thing. I used to walk a lot, it [osteoporosis] has interrupted my walking."

Irene (FG 3) had to modify even less physically demanding activities in order to continue some leisure activities.

> "That's right. I used to take, I used to play bridge a lot in different tournaments, and I used to carry my Obusform with me to put in the chairs as I moved along. But I found that I don't know whether I'm better off or not, I found I don't need Obusform anymore, I sit in the chairs but if the chairs had arms and that was beautiful."

Beth (FG 1) could still participate in leisure activities but had to pace those activities or other activities the following day.

> "And we tend, if we want to do something or go out or go to a theatre, and then you do something. I need a day after I do anything, I need a day of rest."

Participants discussed traveling with osteoporotic vertebral fractures as something they either limited or had to modify how they traveled. Travelling was seen as something that increased fatigue and pain. Jess (FG 3) wanted to travel but had to modify her accommodations in order to feel safe.

> "Well I know how to do my own bath tub, but if I go someplace, even to a hotel or anything, I don't take a bath, I have a shower because I am nervous getting into the bath tub."

There was good information sharing among the participants with respect to how to modify their travel. The participants seemed to enjoy sharing tips and information about ways they had learned to travel with their condition. Shirley (FG 3) provided some tips about travel assistance.

> "Yeah, you can, when you buy an airplane ticket, you can ask to have extra assistance. And they were good, [they] let you go on first."

Natalie (FG 3) summed up the focus groups feelings about travel in general.

> "I don't enjoy travelling as much as I did, you know."

4.4.1.2 Living Arrangements

In some cases osteoporotic vertebral fractures made participants question their ability to remain independent in their own home. Some participants thought with some additional outside assistance, such as home making services, personal care services, and support from friends/family, they could stay in their own home. Some participants decided they could not stay at home and needed to consider moving to an assisted living facility. These decisions caused significant life changes. Due to her limitations Joan (FG 1) was unable to manage a detached home and she moved to a home that involved less physical outdoor maintenance.

> "And I had to, I was twenty-seven years there and I moved now to a condo bungalow but it is very accessible."

As her limitations progressed, Joan (FG 1) has had to consider additional changes to her living arrangements.

> "So, I do find that I have to seriously think of assisted living possibly and that's really hard for me."

Some participants did have family who helped them while others did not have family nearby. Beth (FG 1) did not want to impose on her family as she felt they were too busy.

> "I mean one of them lives up in ______ [city]; she works all night, he works all day. I'd be there by myself all day. What's the point in that? I have a daughter in _____ [city]; it's the same thing. And I have a son that lives here in [city], so there you go. I mean he's married and they're busy and they have grandchildren in the city."

Doris (FG 2) had to give up her summer cottage because she could not physically manage the outdoor maintenance. Overall, living arrangements were a very personal thing for participants.

> "I think it [osteoporotic vertebral fracture] ended your farming life, didn't it? It certainly ended my, my cottage life, gardening, and outdoor work and that sort of thing."

Beth (FG 1) came to the realization on her own that she needed to change her living arrangements.

> "And so you just, I just couldn't stay alone anymore. I had to do something, so I did it [moved]."

4.4.1.3 Transportation

The participants in the focus groups used different modes of transportation. Some still drove their car everywhere, some no longer drove, some drove only in certain conditions, and some relied on friends and family for transportation. The key result was that the women found transitioning from driving themselves to using other modes of transportation a challenge. Joan (FG 1) found relying on others for transportation hard to coordinate.

> "I have a lot of friends who'd help me drive and I'll give them gas money, you know, but sometimes I can't. And if you have two appointments on one day, that's, trying to coordinate that is hard."

Public transportation was seen as costly and inconvenient by most participants. They indicated they could not be as spontaneous with their outings if they had to pre-book adapted transit (public transportation adapted for people with disabilities) while city buses were not convenient because of infrequency. City buses also required one to be able to walk long distances between bus stops. Taxi cabs were expensive but more convenient with respect to timing. Mary (FG 1) found the discussion around transportation helpful in terms of satisfying her future needs.

> "See, I've never used any of these resources yet because I drove. So it's good to know about them but I would hate the waiting time."

There was a considerable amount of sharing between participants in the focus groups about the benefits and drawbacks of different types of transportation. Transportation available through Meals on Wheels was discussed at length. This organization provides limited transportation services in addition to meal services. Mary (FG 1) liked the service but did not like the lack of spontaneity and limited rides available.

> "You have to give them five days notice" ……"Oh yeah, but see now with Meals, you can only get one ride a week."

4.4.1.4 Weather and Seasons

The weather and seasons were a significant topic of discussion. The winter season was marked by increased anxiety related to the potential for falling on the ice. As a result, participants found they went out less during the winter months and when they did go out they were more anxious. Irene (FG 3) summed this up for most of the women.

> "I don't go out when there is any ice and snow."

Participants also discussed the effect of winter on their mood. They reported that because they went out less they found they tended to get slightly depressed during the winter. Mary and Beth (FG 1) discussed how winter affected their ability to get outside.

> "The seasons, what season it's in makes a difference. I think the spring and the fall are great, but the long winters, really, we get sort of (the blahs) inside." (Mary)

> "I can only walk maybe one block at a time, you know. And with the walker, it's better but, with winter, we have such a long winter, we get sort of stagnant." (Beth)

The women agreed with Beth (FG 1) that seeing the sunshine during the winter months made this season more bearable.

> "And if the sun is shining, the sun's shining and it's great."

Environmental adaptation involved the women finding ways to modify their environment in order to continue participating in the lifestyle they had before sustaining an osteoporotic vertebral fracture. Identified needs included information about safety in the home, how to modify their environment in a cost effective way, how to adapt to different modes of transportation, how to maintain independence in the home and options for when they are no longer able to manage at home. Desired programs and services included flexible, low cost transportation and meal services.

4.4.2 Functional adaptation

4.4.2.1 Activities of Daily Living

Osteoporotic vertebral fractures had a negative effect on how participants managed activities of daily living (ADL). The following are the areas in which the women expressed a decline in abilities: cleaning, cooking, dressing, personal care, ability to lift heavy items, and general daily functioning. They required more assistance with homemaking, groceries, meal preparation and clean up. Vacuuming was difficult to do and the women indicated it was recommended by their physicians that they do not vacuum after vertebral fractures. Joan's (FG 1) story of how she manages ADLs outlines some of these challenges.

> "I have to have a little bit more help as I said, and I try to find something. I have somebody everyday for hygiene or for homemaking. And friends, I have a wonderful lot of friends who come in, who drop by and will give me sometimes food which I'll heat up. I try to buy food that's specially made, you know, at Loblaws which is the blue low fat stuff. And all we do is put it in the freezer and things. Well, you just, you can use it and you don't have to do preparation. I can't stand at a sink for a long time, I might sit on my walker if I'm going to do something."

Beth (FG 1) found that having someone come in and assist with homemaking services allowed her to engage in more leisure activities that were important to her.

> "See, where I am, we have a housekeeper who comes in every morning and they make the bed and straighten up, empty the waste baskets, clean the sink, clean the toilet......and if you have to do that yourself it's not so easy, it tires you"

While the participants saw the benefit of having someone come in and help with cleaning tasks they also indicated that the cleaning staff did not do as good a job as they would, so they saw a trade off there. Mary (FG 1) provided typical example of how particular the women were about cleaning.

> "Nobody would ever do housework the way that I did. They don't see the corners, they run though the middle as fast as they can."

Joan (FG 1) found dressing and finding alternative ways to dress herself a challenge.

> "Dressing, it [OVF] impacts dressing. You need things that you can put on easily, elasticized and no buttons. Sort of, I have problems doing up buttons 'cause I have rheumatoid. But with the osteo, I think putting on socks and things, trying to bend over, and needing help from somebody to help you."

Cooking and ways to adapt cooking were discussed and some of the main difficulties the women encountered were standing while cooking, clean up, and fatigue. Betty (FG 2) found clean up to be especially difficult.

> "I can get the cooking done, but it's the clean up that's, the dishes and standing and getting that all cleaned up."

Betty and Doris (FG 2) exchanged ideas about how to find ways to make meal preparation easier.

> "I even think that I try now to make, to cook potatoes, enough for two days and other vegetable. I mean, if you could get them in the fridge, they don't deteriorate too much." (Betty)

> "I have recipes for one pot cooking. That saves all those extra meals and recipes put you through the different procedures to which to cook first and which one last." (Doris)

4.4.2.2 Pacing Activities

The women described a need for information about how to pace themselves in all areas of the daily lives. Participants recognized the need to pace their activities, however they acknowledge that they didn't always do it. Mary, Beth, and Joan (FG 1) all agreed that pacing was difficult to do. Mary (FG 1) in particular found pacing difficult and acknowledged doing things she shouldn't. Once their fracture had healed, the participants tended to engage in physical activities they knew might increase their discomfort but they desired to return to the activities they could prior to the fracture.

> "Yeah, pacing yourself is very hard, I think." (Beth)

> "Yeah, it is very hard." (Joan)

Beth (FG 1) acknowledged that to be able to participate in certain leisure activities they would need to pace.

> "Oh, yes. That's more important [a day of rest after activity].......and an afternoon nap, I always take an hour or an hour and a half every afternoon lying on the bed. I just can't function." (Beth)

The result of this discussion was that the women identified not only a need for information about how to pace activities but even more importantly they had to come to terms with the fact that they need to pace their activities in order to conserve energy.

4.4.2.3 Assistive devices

There was much discussion about the benefits of assistive devices and suggestions about what assistive devices worked and how they were accessed through the health care system. The participants spent much time, essentially by trial and error, to find adaptive devices that helped them to complete their activities of daily living more effectively. Joan (FG 1) discussed openly the financial challenges of finding assistive devices.

> "The other thing we didn't touch on is perhaps finances. You know, you suddenly find you're spending more money and needing more equipment..........And I already found I'm on long-term disability and I have to budget carefully. And I suddenly found I needed a bed rail. And though I have insurance, it wouldn't cover that. And I have to get a doctor's letter for covering my security thing at night. You know, I have a bell that rings, one of those things, yes, but I have it around my neck. But I didn't realize all these things add up."

Beth (FG 1) discussed her challenge with finding a back brace.

> "When I took the, these broken, these two vertebrae that fractured, he [physician] said he not only didn't want to operate because it was too serious and he said, " I won't operate because your bones would never hold the screws." So he prescribed a brace. So I wore a brace for four months, and first of all, it didn't fit properly and it cost me $1,300, and I complained, complained, complained about it not fitting. And finally, he really went after them and said, " Look, do something about it or else we're going to go get her a new one." And they tried to fix it but by that time I'd worn it for two and a half months or so."

Assistive devices used by the participants included those that helped with mobility such as walkers, special seats for care and chair, hospital bed, and wheelchairs and those that help with ADLs such as back brace, posture bra, reachers, step ladders, medical alert bracelet, back belt, carpet sweeper instead of vacuum cleaner, and long handled bath cleaners. Beth and Joan (FG 1) found trying to find ways to adapt personal care and dressing was an area where they experienced challenges. Beth (FG 1) liked knowing she was in an environment where if she needed more support with dressing it was available.

> "I think putting on socks and things, trying to bend over, and needing help from somebody to help you. In the retirement home, they'll let you dress and do things but there are always people available who can put your socks on."

Joan (FG 1) found she had to wear different clothing to adjust to the changes in her body.

> "The other thing I really found and I'd never noticed this before is wearing of a bra or anything tight around your ribcage or your back. And I cannot wear one to get excruciating discomfort against intercostals muscles here where they were fractured. But I had to adjust, you know, now I, between you all here, I don't wear a bra, I wear these vest things because it just hurts too much. And if it pulls your shoulders down too."

Betty (FG 2) had the help of her family in finding assistive devices that would assist her to clean independently. By finding a long handled sponge she was able to clean her tub/shower without overhead reaching, which is contraindicated for someone with an osteoporotic vertebral fracture.

> "Like cleaning out your bath tub with a sponge on a long handle."

Natalie (FG 3) used a grab bar to help with getting in and out of the tub.

> "But we applied a hand, you know, a grab bar because the bath tub is very high, and I can't get into it without hanging on. We installed the grab bar, and then just to have a, a stand option."

There was considerable agreement in the need for assistive devices, need to know the costs in advance, and the need for assistance in order to purchase the most appropriate assistive device. There was a fair amount of trial and error in finding the right assistive device.

The focus group participants used the session as an opportunity to talk amongst themselves and share ideas about what worked and what didn't. Joan (FG 1) found using an adjustable bed helped with getting in and out of bed.

> "One of the best things I found, I got a bedside rental from the Community Care Access Center and I put it in here because I thought, if you can use the side bars to pull yourself over; I was having a lot of trouble pulling myself in bed. I have an

> electric bed as well and that's really advantageous for somebody who can't, because you can't really pull up if your ribs are sore."

Shirley (FG 3) found using specialized seating helpful to manage when engaging in activities.

> "The other thing are special seats when riding in a car or sitting here in a chair or a computer, I find, with the fractures, I needed to try and sit up and lean against something soft sometimes. So those were specific things which made it better."

Participants looked towards their health care professionals to educate them about the financial impact of assistive devices.

> "So I think people at the doctor's should tell you, you know, you may have to buy more equipment." (Beth FG 1)

In summary, the needs that emerged from discussion about *functional adaptation* included the need for knowledge about appropriate *assistive devices*, how to access them, how to use them properly, and cost. The programs and services needed primarily focused on homemaking services, while the programs and services wanted included grocery shopping, resource centers, and support groups for advice from others going through the same changes. *Activities of daily living* included homemaking, personal care, cooking, and any other activity the participants felt was a part of their life including leisure activities. Education about *pacing activities* was important to the participants as it affected how they managed their ADLs, leisure activities, and fatigue.

4.4.3 Emotional adaptation

4.4.3.1 Appearance

Appearance was a topic passionately discussed by participants. It focused around changes in appearance due to kyphosis of the spine, posture, and inability to find comfortable clothing. The kyphosis of the spine was something with which the majority of women indicated they had difficulty coping. This gradual change in appearance was quite emotional for the women. Betty (FG 2) did not like the way she looked because of the changes in her appearance.

> "I just feel nobody should be looking at me. My stomach, you know what happens. Your stomach comes out the front."

Betty and Doris (FG 2) also found it difficult to find clothing that fit and was comfortable. They no longer found shopping for clothes a pleasant experience.

> "What I look like. You know, I got this great hump in the back and I can't get clothes that really fit in the store anymore." (Betty)
>
> "Yeah, that's something. Buying clothes, they're all too long." (Doris)

Some women already had significant changes in the shape of their spine and were quite conscious about their appearance. It was interesting to note how participants reacted to one of the posters produced by Osteoporosis Canada. It depicts a woman with severe kyphosis to demonstrate the effects of vertebral fractures. The following are responses from the women and what they see as reminders of their appearance that they find quite difficult.

> "I hate that poster they have hanging up [at the LROP]..........one shows normal and one shows the abnormal, and that's me, more and more." (Betty FG 2)
>
> "Me too, I hate to look at myself after that." (Doris FG 2)

The women noted how even sitting at the table during dinner is affected by changes in the shape of the spine. The following is discussion from focus group three that highlights the participant's difficulty engaging in something as seemingly simple as sitting at the dinner table.

Irene: "I hate sitting to the table. The table top is coming up as if I'll soon be able to press my chin on the table and eat. You know, you're out for dinner and everybody else is sitting up here, and you're all the way down here."

Betty: "That's embarrassing. Even if you sit up straight, you're still not far from the table [surface]."

Irene: "I try to consciously sit over this way, but if I just relax and sit down sometime, I'm over like this, practically in a person's lap next to me."

Irene: "And then you're tired when you sit that way, and it would give you pain when you sit that way."

4.4.3.2 Fear

Fear was discussed by participants in the context of fear of breaking bones, fear of falling, fear of medication side effects, and anxiety when completing activities of daily living. Joan (FG 1) had to find a way to continue living her life and incorporate her fear of breaking a bone. She also talked about how her other medical conditions influenced her fear of fracture.

> "But basically, they've healed [fractures] but I have to be very careful now. I'm scared stiff of the ice, unbalanced and I have [Meniere's] on top of it which is an inner ear balance problem. So if I have a fall, I can't stand straight. I move and I fall back. If I fall back, because I'll shut my eyes, I'm totally off balance, so I've started to use the walker."

Joan (FG 1) acknowledged that fear of falling was always on her mind.

> "Well, I think concern about whether you're going to cause a fracture, another fracture, is, it's always on your mind, you know."

And Jess (FG 3) acknowledged that fear affected her daily life.

> "I find I am more fearful that I used to be. I'm more afraid of falling. I'm just, I slipped in the bath tub two weeks ago, and I just, I finally got myself up but that really scared me. I thought: "Oh no, wouldn't that be awful."

The feedback from the focus groups coincided with the analysis of responses in the demographic form that also indicated a fear of falling and fear of breaking a bone affected participant's ability to participate in activities of daily living.

4.4.3.3 Emotions

The women displayed a range of emotions both positive and negative when talking about their experiences with osteoporosis and fracture. Depression and fear were common threads. For many women having a vertebral fracture led to a decrease in ability to participate in activities they previously enjoyed and were able to complete independently. Doris (FG 2) in particular experienced depression as a result of the life changes due to her condition.

> "Well, mine has been very depressing because I had to give up my summer home and I'm out here for six months, living in an apartment all the rest of the year. I love to get out and garden and just do, and I just loved it."

Betty (FG 2) found the changes in her lifestyle difficult as well.

> "Devastating really, I couldn't even take a step like when I, the worst break I had was helping my husband lift a rabbit cage."

Despite their pain, disability, and struggles with their condition the women also displayed optimism. Natalie (FG 3) found the care of osteoporosis to be better now.

> "The acknowledgement of it [osteoporosis] is much better now than it was even five years ago, don't you think."

Beth (FG 1) found that trying to be as active as possible increased quality of life.

> "You're doing something, doing all those activities are sort of, laughter's meant to be the best thing for healing too, so."

Despite their challenges the women were generally quite positive in their attitudes toward life and their independence.

> "I'm not as particular as I used to be. I still have a lot to do, like with two people all the time [Betty and husband] and I'm thankful for that." (Betty FG 2)

> "Yeah, and fairly independent, I still grocery shop." (Doris FG 2)

4.4.4 Summary – Lived experiences related to adapting to the condition and the need for Information, Programs, and Services

In the sub theme of *environmental adaptation* the study participants had to learn how to adapt their environment because of an osteoporotic vertebral fracture. For the most part they adapted to their environmental on their own. Their experiences indicate a lack of information about how to adapt their environment based on their changing abilities due to the fracture and multiple other co-morbidities. They adapted their home environment to include safety features for falls prevention, they adapted their ADLs and their leisure activities to meet their limitations. There were no programs or services the participants accessed that provided the assistance they needed.

In the sub theme of *functional adaptation* the women learned to adapt their activities of daily living through trial and error and their experiences indicate they found ways to adapt fairly well on their own. It was apparent however that having a group of others to talk with, as occurred during the focus groups, helped the women share ideas and methods of adapting. This opportunity to talk amongst themselves was welcomed by the participants.

Within the sub theme of *emotional adaptation* the women expressed a need for information, programs, and services related to coping with changes in appearance, coping with depression, and coping with fear of falling and future fractures. There were few support services available for emotional support. The women would like to have participated in programs that provided emotional support. Some women liked the idea of a formal support group while others preferred a less formal format where they could talk with someone about their challenges.

4.5 Participant's feedback re: Information, Programs, and Services

Table 3 provides a quick summary of utilized and desired sources of information, program and services that emerged during the focus groups sessions at the time women were diagnosed with osteoporosis and a vertebral fracture. Barriers associated with utilization of programs and/or services are also included.

Table 2 *Summary of Information, Programs and Services Used and Desired by Participants Regarding Osteoporosis and Specific to Vertebral Fractures*

Information Used/Found Helpful	**Information Desired**
Information from LROP	Prevention information (Calcium/Vit D)
Osteoporosis Canada	Exercise specific for vertebral fractures
Exercise information from CCAA	Pain coping strategies
	Medication information
	How to get out of bed properly
	Strategies to cope with day to day activities
	Education about how health care system works
	Behaviour change
	Nutrition Information
	Importance of prevention early in life
Barriers	
No information was received from physician	
General lack of information	
Nothing for the lay person	
A lot of mis-information	
Types of information received	**Sources of Information**
Pamphlets and brochures	General practitioner's office
Books	Pharmacist
World wide web based	Specialist's office
Magazines	Nurses at specialist's and GP's offices
OC 1-800 number	Library
Calcium questionnaire	Osteoporosis Canada (at events and online)
On-line calcium rich recipes	Physiotherapist
	Internet
	Family Members
Programs and Services Used	**Program and Services Desired**
Exercise programs	Support groups for vertebral fractures
Transportation services	More flexible and available transportation services
(Meals on wheels, bus, car)	Education sessions about vertebral fractures
Meal services	Pain management programs
Focus group discussion	Flexible exercise programs
Family and friends' assistance with ADLs	More programs about assistive devices ADLs
Homemaking services	More knowledge about available support services
Barriers	
Transportation (availability, cost, waiting time and scheduling)	
Parking (availability and cost)	
Weather, Motivation	
Finding someone to talk to about an exercise program	
Financial constraints of obtaining assistive devices	

4.6 Environmental Scan

This environmental scan is a review of information, program, and services about osteoporosis currently available in the London area. This scan will assist in determining discrepancies between available information, programs and services and the needs expressed by the study participants. This scan is divided into two sections: Information and Programs & Services.

4.6.1 Information about osteoporosis

One of the main sources of osteoporosis information is Osteoporosis Canada. Osteoporosis Canada is a national non-profit health charity established in 1982 serving those who have or are at risk for osteoporosis. It provides awareness and education to the general public through Public Service announcements, health fairs, speaking engagements, and print advertising.

Osteoporosis Canada's print material includes the print material/brochures listed in Table 3.

Table 3 *Summary of Osteoporosis Canada's Print Material*

Brochure	Purpose	Target Audience
Osteoporosis: Are you at Risk?	P/E - Outlines risk factors for OP	GP
Your Guide to Strong Bones (multiple languages)	P/E - Physician summary sheet re: calcium, vitamin D, exercise	Pt
Osteoporosis and You: A Women's Guide	A comprehensive booklet for women/prevention & treatment	Pt (Women)
Living well with Osteoporosis	A booklet for men & women/disease management for those with OP	Pt (Men & women)
Calcium fact sheet	Detailed calcium info/prevention & management of condition	GP/Pt
Diagnosis fact sheet	Detailed diagnosis info/prevention & treatment information	GP/Pt
Drug treatment fact sheet	Detailed drug information/treatment & management of OP	GP/Pt
Physical activity fact sheet	Detailed physical activity info/prevention & management of OP	GP/Pt
Men & osteoporosis fact sheet	To educate men about OP/prevention	Men
Secondary osteoporosis fact sheet	To educate general public & health care professionals about secondary OP/prevention & management of OP	HC/Pt/GP
Osteoporosis & osteoarthritis fact sheet	For general public/outlines difference between OP & OA	GP/Pt
Canadian Osteoporosis Patient Network COPN	Registration for COPN/patient support through online and print updates biweekly	Pt
Quick Reference Guide	Osteoporosis treatment pathway	HC

PURPOSE: E (Education), P (Prevention), D (Diagnosis), M (Management), N (Networking)
TARGET AUDIENCE: GP (General public – with or without OP) Pt (Osteoporosis patients) HC (Health care professionals)

A review of Osteoporosis Canada's print materials indicates a substantial amount of information related to osteoporosis prevention but less for management of osteoporotic vertebral fractures. Two booklets 'Living Well with Osteoporosis' and 'Osteoporosis and You: A Women's Guide' address assistive devices, activities of daily living, falls prevention and safety in the home. Other informational resources produced by Osteoporosis Canada include instructional videos and DVDs about physical activity and osteoporosis. The most recent DVD entitled 'Osteoporosis: Meeting the Challenges' was produced to address osteoporosis and physical activity was released in February 2010.

Osteoporosis Canada's educational print information is available directly from Osteoporosis Canada as well as through physician's offices, Middlesex London Public Health Unit, Family Health Teams, Community Health Centers, London Intercommunity Health Centre, and the Cherryhill Healthy Aging Program. While print information is available through the above centers, the DVDs are only available directly from Osteoporosis Canada. Other informational resources available in the community include brochures and booklets produced by pharmaceutical companies (Merck Frosst, Pfizer), pharmacies (Rexall, Shoppers Drug Mart), community organizations (Dairy Farmers of Canada/Ontario) and private organizations (Philips Lifeline). Numerous websites related to osteoporosis are available through the internet. A search of the term "osteoporosis" using Google resulted in 11,300,000 results and a search of the term "osteoporosis vertebral fractures" using Google resulted in 4,180,000 results. Table 4 below lists the websites associated with the search term "osteoporosis vertebral fracture" and a brief description of the content and sponsor.

Table 4 *Top 10 Websites Listed from Internet Search of term Osteoporosis Vertebral Fracture*

Website	**Description**
www.car.ca	Canadian Association of Radiologists, guidelines for reporting of vertebral fractures for Radiologists
www.oakvillebonecentre.com	Journal article linked from website, academic article
www.bigbackpain.com	Osteoporosis information, sponsor of site not known, links to National Osteoporosis Foundation
www.cmaj.ca	Journal article link from website, academic article
www.coa-aco.org	Canadian Orthopaedic Association article about vertebral fractures
www.cadth.ca	Canadian Association for Drugs and Technologies in Health, article about Raloxifine
www.fhs.mcmaster.ca	McMaster University document
www.osteoporosis.ca	Osteoporosis Canada, non-profit organization. Patient focused
www.osteoporosis.ca	Osteoporosis Canada, non-profit organization Patient focused
www.zelostherapeutics.com	Advertisement of clinical drug trial, for profit organization

Note: Search term: **Osteoporosis Vertebral Fracture**

The Healthline (www.thehealthline.ca) is an on-line web based registry of regional community resources for a wide range of health information including osteoporosis. The London library has a main branch, 16 satellite branches and a Home Library service that have books available about osteoporosis. A search of osteoporosis resources revealed 25 publications and one DVD. Of the 26 resources available 17 books were at the Central branch and six books were available at three branches across the city. The resource topics available were general prevention and management, physical activity, and nutrition.

The study participants indicated that there was no single source or method for obtaining osteoporosis information. While they noted that their general practitioners were seen as a credible source of information not all participants found information through this avenue.

4.6.2 Osteoporosis Program and Services

In the London area there is currently one specialty medical program that treats individuals with osteoporosis, the London Regional Osteoporosis Program located at St. Joseph's Health Care London. This regional clinic is staffed by three specialists and a staff nurse. They serve patients from London and the surrounding 10 counties (Middlesex, Elgin, Lambton, Essex, Kent, Oxford, Huron, Perth, Bruce, and Grey) with a total combined population of over 1.5 million people.

Physical activity programs that focus specifically on osteoporosis exercises are available at the Canadian Centre for Activity and Aging, Horton Street Senior's Centre, and the Kiwanis Senior's Centre. These three centers offer ongoing instructor lead osteoporosis specific exercise programs. Some private clubs offer exercise programs aimed at the older adult but do not necessarily have osteoporosis specific programs.

In March 2010 Osteoporosis Canada introduced Bone Fit, a certification program for Physiotherapists, Kinesiologists, and exercise professionals. It provides evidence based instruction and education about osteoporosis-safe exercises. This voluntary program is endorsed by and coordinated through Osteoporosis Canada. To date two workshops have been held in Kingston and St. Catherine's, Ontario. Once certified, participants can then take their knowledge back to their communities and individuals they serve.

The Canadian Osteoporosis Patient Network (COPN) is organized through Osteoporosis Canada and consists of patients with osteoporosis and their caregivers from across Canada whose goal is to provide support to those living with osteoporosis. Patients receive osteoporosis information via email and traditional mail every two weeks. In 2009 through COPN, Osteoporosis Canada held two Virtual Forums, one regarding medications and one regarding physical activity. The Virtual Forums are a web based discussion groups that require patients to have a computer and internet access. This is an interactive forum where patients can post questions and see and hear the speaker located at a central site.

Osteoporosis Canada has a local chapter, the London & Thames Valley Chapter that supports individuals with osteoporosis locally through education forums and dissemination of print material through health fair displays. Currently, there are no osteoporosis support groups running in the London area. In addition, Chronic Disease Self-management programs are resources that can help individuals manage a chronic health condition. Currently there are no CDPM programs that target osteoporosis specifically in the London area. The only program that addresses osteoporosis at all is available through the Arthritis Self-Management Program (includes an osteoporosis component). The local South West LHIN has recently launched a self-management program however it does not target osteoporosis specifically but rather chronic disease prevention and management in general.

The study participants indicated that there was no consistent way that they were linked with community programs and services such as physical activity programs. According to the study participants the most consistent way patients can be linked to osteoporosis programs and services through their primary health care provider and/or specialist. At this time there is no central referral process that links patients to programs and services in the community. The mandate of the London Regional Osteoporosis Program is to treat the medical aspect of the condition.

4.6.3 General Programs and Services for Senior's

A review of general programs and services available to seniors in the London area was included in this environmental scan to demonstrate the variety of programs and services available to seniors, a large portion of who have osteoporosis or are at risk for osteoporosis. Some of these resources have osteoporosis information available. The programs and services listed here could be an avenue for dissemination of information in the future.

Local Physical Activity programs for seniors are offered through the Kiwanis Senior's Community Centre, Hamilton Road Senior's Centre, Berkshire Club Senior's Program, Huff N' Puff Senior's Fitness Association, and Hutton House (for individuals with a disability). London Council for Seniors and 3rd Age Outreach (Parkwood Hospital) provide programs for seniors. There are two YMCA fitness centers in London (Centre branch and Bob Hayward branch). The above centers do not have osteoporosis specific exercise programs but they do offer exercise programs tailored to an older population many of whom have osteoporosis.

There are numerous Community Centers in London with seniors programs including the Boyle Community Centre, East London Artisans Centre, North London Optimist Centre, South London Community Centre, Stronach Community Centre, Kinsmen Recreation Centre, Crouch Neighbourhood Resource Centre, Glen Cairn

Community Resource Centre, Northwest London Community Resource Centre, and the East London Community Resource Centre. These centers are a community gathering place for events and offer recreation and leisure programs for seniors.

Local Health Centers include the London Intercommunity Health Centre, VON Community Support Programs, and the Cherryhill Health Aging Program, all of which have osteoporosis information available to their clients.

There are numerous general adult fitness centers in London. The following are fitness centers that have programs for seniors but not specific to osteoporosis. Fitness programs are the Physical Maintenance Program at Parkwood Hospital, Bob Hayward YMCA, Centre Branch YMCA, Chelsey Park Retirement Community Health Club, Parkwood Fitness Centre, Horton Street Senior Centre, and the Athletic Club STAR program for Seniors.

CHAPTER 5

DISCUSSION

A phenomenological approach was used to explore the patient perspective with respect to the needs for information, programs, and services of a person living with osteoporotic vertebral fractures. The research objectives of this study were: to explore the needs of individuals with osteoporotic vertebral fractures living independently in the community; to conduct an environmental scan of information, programs, and services related to osteoporosis currently available in the London area; to identify gaps in information, programs, and services in the London area related to the management of osteoporosis, and in particular osteoporotic vertebral fractures; and to review the results of this study to determine the potential to inform the creation of a Needs Assessment questionnaire specific to osteoporotic vertebral fractures.

5.1 Overview of Experiences

The findings of this study form a framework of how women experience living with an osteoporotic vertebral fracture. As a summary, the three major themes identified were *journey to diagnosis*, *learning about the condition*, and *adapting to the condition.* The theme of *journey to diagnosis* generated three sub themes, *diagnosis, health care professionals, and health care system*. The women experienced a frustration with diagnosis and appropriate treatment from within the health care system and in particular with their general practitioners. Within the theme of *learning about the condition* there were several sub-themes including learning about *pain and pain management, treatment, medication, physical activity and fall/fracture prevention.* In this theme the women experienced difficulty in trying to learn about their condition and implement strategies to manage their fractures. The Theme of *adapting to their condition* comprised three sub-themes *environmental, functional, and emotional* adaptation. The women were able to manage their condition through trial and error however, had they had the right support (occupational therapy services, emotional support) this process may have been more effective.

While the results section outlines the collective experiences of the women, there were singular experiences that should be addressed. Beth in FG 1 spoke about not listening to her physician's advice and admitted she was not a "role model" for doing as her physician requested. Mary indicated that she would move furniture and heavy objects that she knew she should not do and that this may have contributed to a number of her fractures. She did acknowledge that she had stopped doing this and indicated she wished she had listened to her physician. Doris in FG 2 spoke about how her osteoporotic vertebral fractures ended her cottage life and she spoke about depression in greater detail. Due to the physical demands of maintaining a cottage, such as outside maintenance and interior cleaning, she was unable to manage and had to sell her cottage and live full-time in her apartment. Mary in FG 1 spoke about her first fracture which occurred when a relative moved some furniture in her home.. She went to sit down and missed the chair, as it was in a slightly different spot. Mary was upset with this relative because had the chair not been moved she would not have fallen and fractured. Mary did not initially understand the connection between osteoporosis and fragility fracture.

Figure 2 depicts how the women's experiences and needs changed over time. Based on the focus group results, there was a pattern that emerged regarding the process the women experienced as they went from a diagnosis of osteoporosis to sustaining osteoporotic vertebral fractures. There were common needs that emerged at different stages of the condition. Women at risk for osteoporosis wanted education about prevention and risk reduction strategies (calcium vitamin D, diet, exercise) well before they had low bone density so they could potentially avoid the disease by stopping their bone loss. Women who had already been diagnosed with osteoporosis wanted education about pain management and medications in addition to risk reduction strategies. Those in later stages of disease, who have experienced vertebral fractures, need information, programs and services targeted to activities of daily living, assistive devices, logistical support and emotional support. Barriers that affect these needs include a gap in linking patients to information and a lack of programs and services available for those with osteoporotic vertebral fractures. A lack of communication or dialogue between the patient and health care professional also exists.

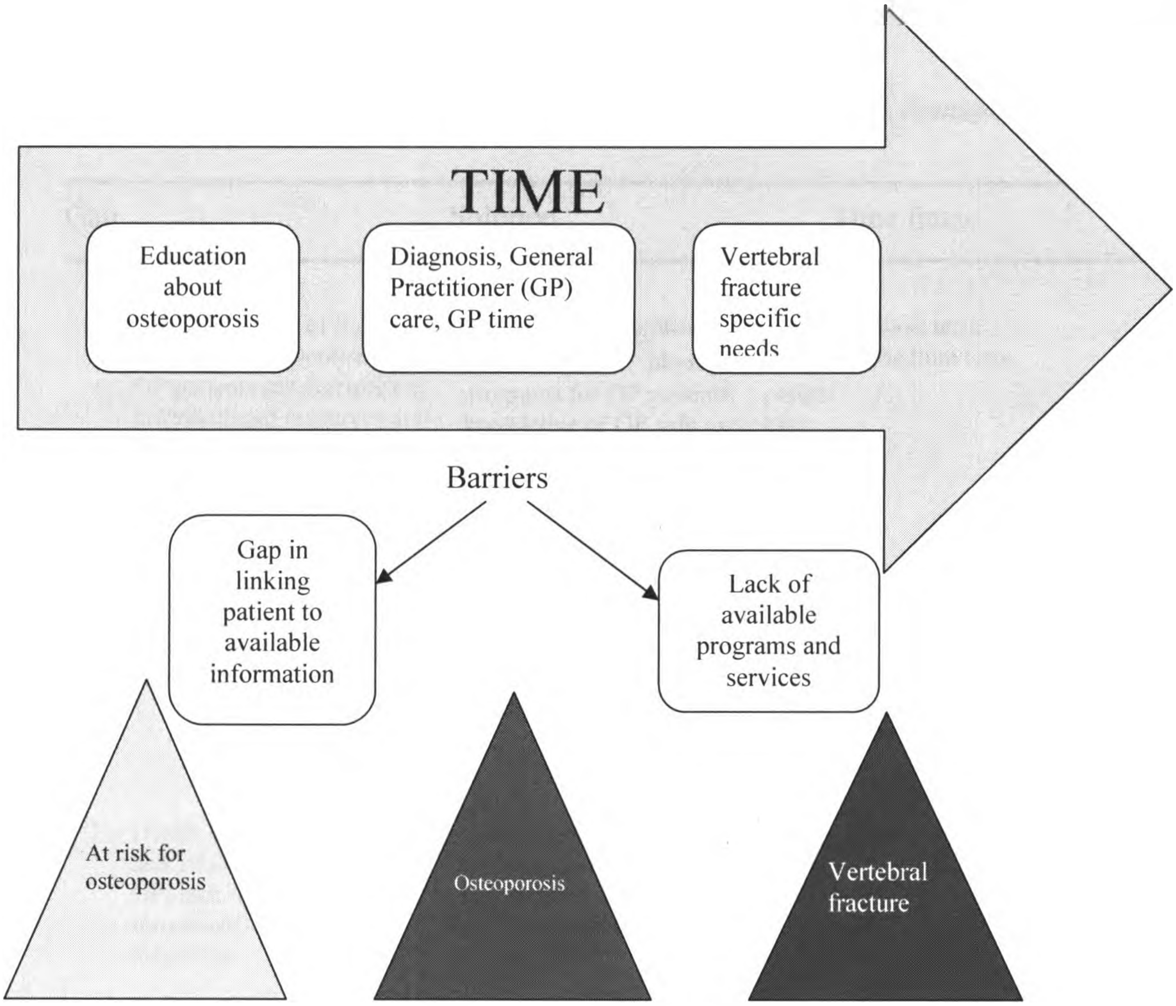

Figure 2. Information, program and services needs timeline

5.2 Identified Gaps and Proposed Solutions

Table 4 below outlines three major gaps in information, programs and services identified by the participants followed by solutions, some vocalized by the participants and some inferred by the researcher. The table includes gaps, solutions, and time frame for implementation of solutions. The gaps were identified based on the experiences of the participants in comparison with available information, programs and services. A gap was considered to be resources the participants wanted now or wished they had in the past when they first encountered a vertebral fracture.

Table 4 *Information, Programs and Services Gaps and Solutions Summary Table*

Gap		Solution	Time frame
1	Limited linking of those looking for prevention and OP patients (no fracture) to informational resources and programs & services.	Creation of an information resource form, ↑ physical activity programs for OP patients, ↑ patient knowledge of OP safe exercises, nutrition resources for patients	Short term Medium term
2	Lack of information, programs & services for those with osteoporotic vertebral fractures.	Occupational therapy services, assistive devices, ADLs, pain management programs, transportation services, Information resource form	Medium to Long term
3	Health Care System: lack of GP knowledge of OP, lack of time available for patient, and delay in diagnosis.	↑ professional education, utilize Family Health Team model, early testing & diagnosis ↑ GP time with patient	Long term

Note: Short Term: 3-6 months, Medium Term: 6-12 months, Long Term: 12-24 months

The results of this study will be discussed below in the context of each gap identified.

5.2.1 Gap 1 Linking of Patients to Information, Programs, and Services

While this study concerned those with osteoporotic vertebral fractures, the participants felt that the information related to prevention of osteoporosis was important prior to sustaining a fracture. This would include risk reduction information, disease management information prior to a fracture, and support after sustaining a fracture. A review of information resources indicates a wealth of information about osteoporosis now available, however the challenge is linking the person to the information relevant to their needs, which depend on the stage of the disease. The first gap then relates to the participants' expressed need to better link patients to general *information* about osteoporosis at the right point in time relevant to their stage of the disease. This gap also relates to the need to link the person to *programs and services* available for prevention and education in the community, such as fitness programs and nutrition (diet, calcium, vitamin D, and supplements).

A local publication that will outline all available information about osteoporosis prevention and management was a solution brought forth by the participants. Current educational information regarding the *prevention and risk factors reduction* of osteoporosis is available through several avenues including Osteoporosis Canada, health fairs, senior's centers & organizations, pharmacies, physician's offices, and community health centers. The time frame listed in the table indicates short-term for the creation of a listing of information, programs, and services and medium term for the dissemination of this resource list to health care professionals, exercise professionals, and senior organizations.

While linking was considered a gap, the *type* and *source* of information received was also considered important by the participants. They wanted the information to be easy to understand, easy to access, and preferably provided through a health care professional. Although participants indicated that a physician was the first choice for delivery of health care information they acknowledged that a nurse, physiotherapist, or pharmacist could be a good source of educational information. The Regional Osteoporosis Program was seen as a good central point of contact for osteoporosis information, however by the time someone is referred to the LROP they are past the prevention stage and more likely in the management stage of the disease. Ribeiro et al.

(2000) found that in a group of women surveyed about their knowledge of osteoporosis prevention and treatment more than half had heard about osteoporosis but did not find useful information. When asked what information they wanted as part of osteoporosis prevention the vast majority did not know what information they would want. Women also indicated their family physician was seen as the most frequently sought source of information about osteoporosis. This concurs with findings in this study with the women indicating they looked to their general practitioners as a credible source of information. They were also dissatisfied with the information received at the time of diagnosis.

Husk, Jensen and O'Riordan (2007) found in an assessment of their falls and osteoporosis program that while the participants were satisfied with the program they are not always helped to understand the services and how to implement recommendations for osteoporosis and falls prevention. Participants expected their health care professionals to be forthcoming and participants did not ask for information. The key seems to be helping participants understand health prevention information presented, so providing information alone may not meet someone's needs, having a credible person to provide health teaching may increase the likelihood of adopting health prevention strategies. This has been the case with a post fracture screening program, where the likelihood of adopting bone health strategies increased with the implementation of a one-on-one educational intervention (Ward et al., 2007; Jaglal et al., 2006) Educating women about credible sources of information other than the family physician is important.

With respect to information about the availability of programs and services for those with osteoporosis the participants in this study wanted community based exercise programs that are osteoporosis friendly, exercise professionals who are knowledgeable about osteoporosis-safe exercises, nutrition resources, and pharmacy resources to address questions about medications. The women advised that by having information, program and services available they could better educate themselves in order to better self-manage their condition. While there were only three physical activity programs in London that offered programs specific to osteoporosis, there were many physical activity centers that focus on seniors and some incorporated osteoporosis exercises into their exercise programs. Study participants wanted physical activity programs that are tailored to their level of ability. Physical activity barriers included weather, season, transportation, and motivation. It is important when creating physical activity programs for those with osteoporotic vertebral fractures and osteoporosis to take these issues into account. As with information listed above, better linking of the individual to existing programs and services would the presence of health care or exercise professional to provide education and support.

Solutions for this issue, proposed by participants, included exercise programs that are flexible and could be completed at home when the weather is a barrier, yet provide enough support to be continued as part of a home based program. Participants acknowledged that they knew physical activity was important for their bone health and health in general but they struggled with motivation to sustain continuity with their programs. By providing education about the importance of physical activity this may increase participation in exercise programs. Participants indicated that had they known the consequences of osteoporosis and associated potential for fracture they would have changed their behavior and engaged in health prevention activities.

Hsieh, Novielli, Diamond and Cheruva (2001) surveyed women about beliefs regarding the prevention of osteoporosis. They found that only when women perceived osteoporosis to be a risk to their health did they engage in preventive behaviours. This is somewhat different from what was discussed by the participants in this study. The women advised that had they known about the risk of sustaining a fracture they would have engaged in prevention behaviours much earlier. However, this is hindsight information based on the participants own reflection after a fracture. Whether the participants would have actually engaged in health change behaviours, without a perceived risk of osteoporosis, is unknown. Jachna and Forbes-Thompson (2005) also found that those with a low perceived threat of osteoporosis were less likely to engage in health prevention behaviors. Burgener et al. (2005) interviewed older adults about osteoporosis knowledge and beliefs. They found awareness of osteoporosis to be high but the older adults interviewed had an incomplete understanding of the disease, which may affect how the participants implemented an osteoporosis prevention program.

Hodsman et al. (2004) found that a structured information and risk assessment program positively affected decisions women made about osteoporosis prevention. This research program was hospital based however, by moving this into the community and combining this model with a support group would fill a gap in the need for information and support in the management of osteoporosis and osteoporotic fractures.

In order to meet the needs of women for preventing and treating osteoporosis it is important to not only link patients to information, programs and services but to also ensure they understand how to implement health promotion strategies preferably through a credible intervention.

5.2.2 Gap 2 Lack of Information, Programs, and Services for those with an Osteoporotic Vertebral Fracture

This gap includes both the limited availability of information, programs and services for those with osteoporotic vertebral fractures as well as the lack of linking of information and programs and services currently available with patients at this much progressed stage of the illness. The most prominent were gaps were noted in pain management, flexible transportation, assistive devices, and activities of daily living. Solutions proposed by participants included more flexible and one-on-one transportation services for appointments, pain management programs, support programs such as support groups, self-management, and peer mentoring models, occupational therapy access for modifying ADLs and utilizing assistive devices, and options for funding assistive devices. The time frame to address this gap was listed as medium to long term, medium term to create and disseminate currently available resources and support programs. Long term time frame was related to the creation of programs and services beyond the scope of osteoporosis professionals such as improving transportation and funding for assistive devices.

Women with osteoporotic vertebral fractures need additional information about strategies to cope with loss of function due to the fractures. Some of the issues noted previously in the literature are a decrease in ability to complete ADLs, ongoing pain, and physical changes to the spine (Papaiouannou et al., 2002). The participants requested information in order to educate themselves about management of the condition that will allow them to make decisions about their care and to then access programs and services that can facilitate maintenance of a good quality of life despite a chronic health condition.

Clarke et al. (2005) found that women defined their health, quality of life, and well-being based on their abilities to participate in meaningful leisure activities. The women in this study also indicated that participation in leisure activities was important to them and they modified the activities to be able to engage in them as long as possible.

Pain control was an important component for the women in order to be able to engage in activities that were important to them. Participants experienced pain well after the fracture had healed. Participants felt it was important for general practitioners to realize that pain control may be an ongoing and not time limited issue. Jensen and Harder (2004) found that by exploring the patient's pain experience and providing non-medical strategies the patients were better able to control the pain and increase their self-efficacy in coping with pain. Strategies included tracking pain levels, talking about pain levels, and coping with ADLs.

A significant gap noted by the participants was the need for more support services in the home, assistive devices and advice on how to manage activities of daily living. Occupational therapy services are not currently routinely available unless a patient has a referral through the local Community Care Access Center. From the focus group sessions it was apparent that only three participants were assessed by the local Community Care Access Center after the vertebral fracture.

There are different options for community based support programs including self-management programs, support groups, and peer mentoring type programs. Each program is unique and offers advantages and disadvantages for different needs. Self-Management programs involve sharing of experiences of those living with an osteoporotic vertebral fracture. In the focus groups some participants discussed the need for programs in their apartment buildings where they could attend not just sessions about osteoporosis but other health education topics. For those patients with more severe vertebral fractures who have many needs a Peer Mentoring program may be of more benefit (Kloseck, Crilly, Hanson, & Speechley, 2010a). This type of program trains seniors in the community about osteoporosis so that they may then act as a mentor to those who need support. The benefit of this type of program would be the support from a peer as well as the one-on-one assistance. One thing that is apparent from the focus groups is that not one program or service will meet the needs of every person with an osteoporotic vertebral fracture.

One of the focus groups was conducted in a rural community to see if there were specific factors that affected experiences in addition to those noted in an urban setting. The rural focus group brought forth one benefit to living in a smaller town with respect to accessing information, programs, and services. In a smaller town there is generally a community centre or a central gathering place that can be used as a point of contact for residents. Utilizing the use of community centers as a hub would be an efficient way to disseminate information to the rural community.

There are a number of different levels of responsibility in providing the appropriate level of services to those living with an osteoporotic vertebral fracture. There are strategies that can be implemented at a personal level, the family level, the health care professional and health system level, and through the organizations such as Osteoporosis Canada.

5.2.3 Gap 3 Health Care System

The women in this research study identified gaps in physician education about osteoporosis, delay in diagnosing osteoporosis, and lack of time with their physician. Their solutions were to increase general practitioner's knowledge of osteoporosis in order to have early diagnosis and testing, start early prevention, to have general practitioners listen more to the patient, and increase interaction time for patients with complex health issues. By the participant's own admission general practitioners today were more aware of osteoporosis but they felt general practitioners could be better informed. The need for older adults to have more time with physicians to discuss their health concerns is part of a larger health care system issue that is beyond the scope of this research project. The time frame for addressing this gap is listed as long term due to the length of time required to make policy changes with respect to health care services and funding.

Jaglal et al. (2003) explored family physician's perceptions of osteoporosis and educational needs. They found that family physicians are confused with respect to clinically managing osteoporosis, complexities of treating osteoporosis in an older population, and they lacked the knowledge of educational interventions. As a result, both the patient and the physician are in need of additional education.

There have been several initiatives over the past 5 years that have been aimed at increasing physician awareness of osteoporosis. In 2002 a pilot project, called the Canadian Quality Circle pilot project in osteoporosis, aimed at improving physician's adherence to Osteoporosis Clinical Guidelines (Ioannidis, Papaioannou, Thabane, Gafni, Hodsman, Kvern, et al., 2007) demonstrated that utilizing a multifaceted approach to engage physicians improved not only their knowledge about osteoporosis but adherence to clinical guidelines as well. This multifaceted approach included training physicians to be peer trainers, provision of osteoporosis educational material, and education regarding clinical guidelines. London, Ontario was one centre for this pilot project and had eight physicians participate in one Quality Circle of seven that were established. In 2008 Osteoporosis Canada mailed out information packages consisting of clinical guidelines to 6000 general practitioners in Ontario, which included 437 General Practitioners in London listed through the Ontario College of Physicians and Surgeons.

The care gap with respect to osteoporosis diagnosis and treatment has been well documented in Canada and Internationally (Papaiouannou et al., 2006; Giangregorio et al., 2006; Elliot-Gibson, Bogoch, Jamal, & Beaton, 2004). The experiences of the women in this study with respect to a lack of appropriate diagnosis, even after a low trauma fracture, are indicative of a care gap in management of osteoporosis. Papaiouannou et al. (2006) found that even though having a fragility fracture is a major risk factor for osteoporosis patients are often not diagnosed and treated in order to reduce the risk of future fractures. Giangregorio et al. (2006) looked at this issue internationally and found that the majority of persons who incur a low trauma fracture do not receive appropriate osteoporosis care. Elliot-Gibson et al., (2004) conducted a systematic review of practice patterns with respect to osteoporosis diagnosis and treatment and concluded that those with fragility fractures received little to no follow up for osteoporosis. One of the barriers noted was time and cost of resources required for diagnosis.

In addition to the participant's suggestions, a potential way to provide information to those with OVF is through a Family Health Team model where there is a comprehensive, holistic approach to health care including the use of a physician, nurse practitioner, nurse, physiotherapist, pharmacist and dietician. Family health teams provide not only primary care services but health promotion, chronic disease management and prevention, self-help programs, rehabilitation, and palliative care (Ontario Ministry of Health and Long Term Care, 2009). This model provides a comprehensive level of care that allows for the appropriate diagnosis and treatment of osteoporosis. The introduction of Nurse Practitioners in the Family Health Team model and in some busy General Practitioners offices may also be a way to alleviate the demand on physicians. Other health care professionals such as physiotherapists, pharmacists, occupational therapists, social workers, and dieticians could also be a source of information to patients.

Giangregorio et al. (2007) looked at needs of health care professionals through completion of the Osteoporosis Knowledge Questionnaire in addition to the completion of an environmental scan. The focus of their study was on knowledge level of health care professionals and their need for educational materials. Findings indicate that health care professionals still require improved understanding of osteoporosis prevention & treatment. A lack of appropriate resource materials was noted. While the focus of this study is on needs of health care professionals, it underlines the focus on needs with respect to information about osteoporosis and how to effectively provide resource material.

The health care system issues that were brought forth, particularly the lack of time physicians take with patients and lack of patient-physician relationship were significant and a barrier to receiving appropriate care. One of the most prominent observations from participants was that they wanted to be "listened to" by their health care professionals, particularly general practitioners. Hovey and Paul (2007) discuss how the patient-health care practitioner communication is a complex experience that has transformed from an "art" of medicine to a "science" of medicine using checklists and standardized questions. They propose a model that moves toward an actual conversation with a patient that allows for "authentic" listening to the patient and understanding through narrative. This model embodies the essence of patient-centered care, where the patient's needs drive the care provided. Patient-centered care has been described as a process that encompasses patient choice, partnership with health care providers, and respect (Law, Baptiste, & Mills, 1995).

In the present study the medical model was the focus for treatment and there was little mention of complementary and alternative medicine (CAM) options to treat osteoporosis and subsequent fractures. The participants did mention the use of ice/heat and massage therapy to cope with the pain of vertebral fractures. Mak and Faux (2010) found that osteoporotic patients in Australia frequently used CAM therapy for osteoporosis with an estimated $696 million dollars spent annually on CAM therapies. CAM consisted of multi-vitamins, acupuncture, tai chi, yoga with the main goal of pain control. Conclusions were that physicians need to be aware of what CAM patients are using in order to avoid potential adverse drug reactions.

In order to meet the needs of women with osteoporotic vertebral fractures the health care system should move towards integration of services and provide education opportunities for physicians and their patients.

5.3 Knowledge Translation Implications

An executive summary of this study will be submitted to senior management at Osteoporosis Canada for review. This may help in planning of future activities and resource allocation within Osteoporosis Canada and the Ontario Osteoporosis Strategy. Two potential areas of interest for Osteoporosis Canada would be 1. the evaluation of print materials which need to be relevant to the severity of the disease; and 2. the development of community based programs and services to assist patients living with osteoporosis satisfy their needs such as physical activity programs, internet based education programs, support groups, assistive devices and adjustments of ADLs.

There are opportunities for Osteoporosis Canada to assist individuals in accessing and using the information available. Osteoporosis Canada has a wide selection of print resources however the messaging of information depends on the level of the condition: those looking to prevent osteoporosis, those with osteoporosis, and those who have sustained a fracture due to osteoporosis (particularly an OVF). Osteoporosis Canada's print information should clearly indicate the stage of the disease each pamphlet or brochure is focused on.

In addition to the gap of linking individuals with information there is also a lack of information available for those with osteoporotic vertebral fractures. Print material that addresses assistive devices, activities of daily living, recreation/leisure activities, and emotional adaptation are areas that could be expanded by Osteoporosis Canada. The Ontario Osteoporosis Strategy has focused on having information available through primary health care venues including physician's office, family health teams, community health centers, and pharmacists.

Participants discussed assistive devices at length yet the material from Osteoporosis Canada and other sources does not provide much information about assistive devices. Only one brochure (Living Well With Osteoporosis), is available from Osteoporosis Canada that has detailed information about coping with osteoporotic fractures. Participants wanted information about types of assistive devices (back braces, beds), how to utilize them, cost, how to access devices, and practical solutions for such things as getting out of bed properly and what type of pillow to use. Participants had tried numerous adaptations on their own in order to try to cope with their limitations and found they had difficulty accessing resources with respect to assistive devices.

Osteoporosis Canada has recently introduced Virtual Forums, the most recent one addressing physical activity and osteoporosis. The web based Virtual Forums are offered 3-4 times per year and provide an option for people to receive Osteoporosis information interactively, assuming they have access to a computer and the Internet. Previous Virtual Forums have addressed medications, nutrition, and fall & fracture prevention, all of which were topics the participants wanted more information about.

The focus group participants talk about several different resources provided by Osteoporosis Canada, however, the service most likely to be of benefit to patients the Canadian Osteoporosis Patient Network – COPN, was not mentioned. The COPN provides members with ongoing updates, through bi-weekly emails and regular mail, based on feedback from members and offers a forum for information exchange. This is another way to link patients with programs & services by referring patients to their local chapters in addition to centralized information sharing. This service was established in

2004 and therefore was not available to the participants in this study at the time of their diagnosis and fracture.

The area of self-management and peer mentoring offers potential for reaching patients with osteoporosis at different stages of their condition and with different needs. Peer mentoring would be of benefit to those who are frailer and need more support (Kloseck, Crilly, Hanson, & Speechley, 2010b). While the London area does not currently offer a peer mentoring program or support group this is an area of future development for the local chapter of Osteoporosis Canada.

The Bone Fit program established in February 2010 has begun to train physiotherapist and kinesiologists to become local experts about osteoporosis, safe exercises and functional fitness. The Break Through Program established in 2007 is a community based program that provides bone health education and strategies (nutrition, supplements and physical activity aimed at reducing the risk of osteoporosis.

This review of new and recently expanded programs offered by Osteoporosis Canada summarizes different options available for individuals to access information, programs and services. It is apparent that there is a need for more detailed information that will address complex needs of the osteoporotic vertebral fracture patients. It is important to ensure osteoporosis educational information is available through primary health care services including physician's offices, pharmacies, family health teams, and community health centers.

The following areas require further development for patients with osteoporotic vertebral fractures: Occupational Therapy services, pain management programs, support programs (self-management and peer mentoring), and identification of patients requiring support through offices general practitioners and through the London Regional Osteoporosis Program. Participants indicated that new strategies should take into account a person's age, severity of osteoporosis, and specific type and source of information dissemination preference. The older women in the focus groups preferred to receive information through physician's offices, libraries, and wanted one-on-one education. The younger women in the groups liked information obtained through the Internet, health care professionals in general, and also wanted one-on-one education. The development of an osteoporotic vertebral fracture patient tool kit should be encouraged and supported.

5.4 Future Directions

Asadi-Lari and Gray (2005) questioned whether a needs assessment questionnaire could be a proxy for a quality of life measure. Their theory is that by meeting the needs of a patient related to a medical condition, would improve their quality of life due to patient's ability to better manage the condition. Asadi-Lari, Packham, and Gray (2003) acknowledged that this is a complex concept with many factors involved in meeting needs. The participants in this study indicated that by receiving appropriate information, programs, and services they would have the resources to better manage their condition, which could imply a better quality of life.

The results of this study indicate that patients of the London Regional Osteoporosis Program, who live with osteoporotic vertebral fractures in the community and reside in London and the area, experienced multiple gaps in information, programs, and services related to diagnosis and management of the condition. Future research could involve the development of a Needs Assessment Questionnaire specific to osteoporosis and vertebral fractures upon further explorations of care needs. The next steps would include interviewing physicians and specialists in the field of osteoporosis to include their opinion about the needs of their patients with vertebral fractures. Additionally, interviews with education coordinators and those who work through Osteoporosis Canada would assist in providing diverse perspectives on patients' needs. A preliminary questionnaire could then be formulated and pre-tested on clinic patients and amended as required. The questionnaire could then be administered to greater number of patients to assist in determining what information, programs, and services are required for a person living with an osteoporotic vertebral fracture.

There is a lack of communication and linking of resources that currently exist for those with osteoporosis. The difficulty seems to be in connecting individuals to resources available. Further exploration of this relationship and potential solutions should be explored.

5.5 Limitations and Scope

There is a significant temporal aspect that needs to be considered in this research study, considering that the participants were diagnosed with the disease between 1995 and 2005 and the environmental scan of information, programs, and services has been completed in 2010 and reflects currently available resources. Osteoporosis Canada was established in 1982 and the Ontario Osteoporosis Strategy was funded in 2005. Both contributed greatly to an increase in availability of information, programs, and services. In this period, pharmaceutical companies and pharmacies have also produced osteoporosis information as treatment options have changed thereby increasing the awareness of osteoporosis in the community. So patients diagnosed five years ago would have had a different experience in obtaining information and access to programs and services than patients diagnosed a decade or more ago. While women recently diagnosed have a better chance of being linked to information, programs, and services; those that were diagnosed with osteoporotic vertebral fractures many years ago still struggle with finding information and support. Participants acknowledged that the availability of information pertaining to osteoporosis increased and became more accessible over time. However, they felt that there was a lack of programs and services specific to osteoporotic vertebral fractures. Efforts to reach out to this sub-group of patients should be made to connect them to the information, programs, and services that are currently available. Hence, the results should be interpreted with this temporal component in mind.

There were several limitations with respect to this research study. The use of focus groups was employed in order to achieve a consensus of opinion and to validate the experiences within the groups. Recruitment of patients was a challenge as participants frequently said they would like to participate however, winter weather in March was a challenge. As a result, conducting research with osteoporosis patients requires attention to the season in order to allow for the best possible rate of participation.

A number of potential participants would have rather engaged in a one-on-one interview not because they didn't like focus groups but because it was more convenient to have someone come to their home rather than travel to a focus group session. The staff nurse at the regional osteoporosis program, who assisted with participant recruitment, advised that she had numerous names of potential participants that were willing to be interviewed however, the added inconvenience of travel and parking (even though these costs were reimbursed) made participation difficult. As a result, this study included a small number of participants in three focus groups. This study did not include the perspective of frail patients with OVF, those with disabilities, cognitive impairments, residing in long term care, immigrants, or French Canadians.

The focus group participants did not represent a culturally diverse population. The results and conclusions were based on Caucasian, English speaking, and relatively well educated women. The experiences of a culturally diverse group of participants and their subsequent need for information, programs and services may be substantially different. The researcher was also English speaking, Caucasian woman, and living in London. Had the focus groups included a culturally diverse group, the experience of the researcher may have been different.

The environmental scan has limitations in that it is not a comprehensive listing of all services related to both osteoporosis and osteoporotic vertebral fractures. The environmental scan completed for this study was meant to give an overview of information, programs, and services available in London.

5.6 Conclusions

The purpose of this study was to explore the need for information, programs, and services of patients living with osteoporotic vertebral fractures in the community. Through a phenomenological approach, utilizing focus groups, the participants were able to express their needs for information, programs, and services. Through this format, the author was able to understand and report needs that would facilitate better dissemination of information and creation of appropriate programs and services that would enable individuals with OVF to improve their quality of life.

An environmental scan of currently available information, programs, and services in the city of London revealed gaps between existing and needed information, programs and services. The scan and feedback from participants were explored within constraints of timing of diagnosis. The participants were diagnosed 5-15 years ago and the scan was conducted in 2010 suggesting that significant improvements have been made in dissemination of information and awareness of the condition in the past decade.

The focus on this study was on osteoporotic vertebral fractures, however the participants indicated that osteoporosis is a precursor to developing fractures and requires improved prevention strategies. As a result, the area of osteoporosis in general was included in the study outcomes. Three major areas were identified as gaps that affected the access to and utilization of information, programs and services. They included linking of individuals to osteoporosis information, programs and services for those with osteoporosis; limited information, programs, and services for those with an osteoporotic vertebral fracture; and general practitioners/health care system. The results of this study will help Osteoporosis Canada and other organizations better allocate resources and make well informed decisions about information, programs and services available to those with osteoporotic vertebral fractures.

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Appendix A
Ethics Approval

Office of Research Ethics
The University of Western Ontario
Room 4180 Support Services Building, London, ON, Canada N6A 5C1
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca
Website: www.uwo.ca/research/ethics

Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. A. Zecevic
Review Number: **15718E** **Review Level:** Expedited
Review Date: December 03, 2008
Protocol Title: Management of osteoporotic vertebral fractures: The patient's perspective about the need for information, programs, and services
Department and Institution: Faculty of Health Sciences, University of Western Ontario
Sponsor:
Ethics Approval Date: January 08, 2009 **Expiry Date:** December 31, 2010
Documents Reviewed and Approved: UWO Protocol, Letter of Information and Consent, Advertisement.
Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) all adverse and unexpected experiences or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. Joseph Gilbert

Ethics Officer to Contact for Further Information			
☐ Janice Sutherland	☐ Elizabeth Wambolt	☐ Grace Kelly	☑ Denise Grafton

This is an official document. Please retain the original in your files.

cc: ORE File
LHRI

Appendix B

Management of Osteoporotic Vertebral Fractures: The Patient's Perspective About the Need for Information, Programs and Services

Principal Investigator: Aleksandra Zecevic, PhD
Faculty of Health Sciences, University of Western Ontario

Co-Investigator: Patricia Versteegh, MSc (can.);

Letter of Information

Dear: ____

We invite you to take part in this study that will look at the needs for information, programs, and services of people living with osteoporotic vertebral fractures. This letter contains information to help you decide whether or not to participate in this study. It is important for you to understand why this study is being conducted and what it will involve. Please take the time to read over this material and feel free to ask questions if anything is unclear or if there are words that you do not understand.

What is the purpose of this study?

It is estimated that 1 in 4 Canadians have osteoporosis. Vertebral fractures sometimes occur due to osteoporosis and can result in a change in quality of life. While there is information, programs, and services available in the community, it is unclear if they match the needs of individuals diagnosed with vertebral fractures. The purpose is to explore what are your needs for information, programs, and services in the community and how they might influence your quality of life.

Initial here: ________

Why have you been contacted?
You have been contacted because you are a female, you live in the community, and you have been diagnosed with an osteoporotic vertebral fracture.

What is involved if you choose to participate?
This research study will be conducted at the London Regional Osteoporosis Clinic at St. Joseph's Health Care in London. We would like to invite you to participate in a focus group session with 5-7 other women that will last approximately 60 to 90 minutes. During the focus group we will discuss your needs for information, programs, and services related to osteoporosis. We will also ask you to complete a questionnaire with demographic information. Focus group discussion will be audio-recorded to allow us to analyze the data later on. Audio-recording of focus groups is mandatory so if you do not wish to be audio-taped, you should not participate in the study. We will compensate your expenses for parking or will pay a taxi to bring you to and from the focus group session.

What happens to the information gathered in the study?
Data collected in the focus group and the questionnaire will be later analyzed and eventually published in a scientific paper. To protect your identity, your name will be replaced with a unique code that will be used to identify participants in audio-recordings and questionnaires. All hard copies of the data will be locked in a cabinet in a secure office at the University of Western Ontario, where only the investigators will have access. All data will be destroyed after 7 years.

What are the risks and discomforts to you if you participate?
There are no known risks associated with participating in this research. However, some people may experience emotional stress when recalling specific memories related to osteoporotic vertebral fractures. You are free to choose what you will and will not discuss. You may ask for specific information that you have shared to be removed from typed versions of the focus group session.

Initial here: ________

What are the benefits to you if you participate?

There are no known personal benefits associated with participating in this study, but you will assist in developing or changing available information, programs, and services for people with osteoporotic vertebral fractures. Your participation is making a contribution to the osteoporosis research.

Voluntary Participation

Participation in this research study is voluntary. You may refuse to participate or refuse to answer any questions and withdraw from the focus group at any time with no effect on your future care. However, any information collected up to that point, may still be used in the study.

Other Pertinent Information

Please note the consent form attached to this letter. Should you be interested in taking part in this study, please sign the consent form and contact Patricia Versteegh at XXX-XXX-XXXX.

If you have any questions or concerns regarding this study, please contact the Principal Investigator, Dr. Aleksandra Zecevic at (XXX) XXX-XXXX. If you have any questions about your rights as a research participant or the conduct of the study you may contact Dr. David Hill, Scientific Director, Lawson Health Research Institute at (XXX) XXX-XXXX. Representatives of The University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

This letter is for you to keep. You will also be given a copy of the consent form if you agree to participate.

Initial here: ________

Appendix C

Management of Osteoporotic Vertebral Fractures: The Patient's Perspective About the Need for Information, Programs and Services

Principal Investigator: Aleksandra Zecevic, PhD
Faculty of Health Sciences, University of Western Ontario

Co-Investigator: Patricia Versteegh, MSc (can.);

Consent Form

I have read the Letter of Information, have had the nature of the study explained to me, and I agree to participate. All questions have been answered to my satisfaction.

______________________________	______________________________
Name of the Participant (please print)	Signature of the Participant
______________________________	
Date	
______________________________	______________________________
Name of person obtaining consent consent	Signature of person obtaining

Appendix D

Demographic and Information Form

Part A: Personal Information

ID#________________________

Year of Birth: ________________

Place of residence: ______________ Postal code ________________

City: _______ Rural: _________ (Check one)

Occupation: ________________________________

Education: _____ Grade 12 or less
_____ High school diploma
_____ Post-secondary education

Marital Status: _____ Single
_____ Married
_____ Divorced
_____ Widow
_____ Common-law

Are you a primary caregiver? _____ Yes _____ No

Do you receive care in your home? ____ Yes ____ No
If Yes, what type of care? ______ Home making services
______ Personal care services
______ Other

Who provides the services? ______ Family member
______ Outside agency

Type of home: ________ Single Family
________ Condominium

_______ Apartment
_______ Assisted Living

Income: _______ Less than $10,000/year
_______ Between $10,000 and $25,000/year
_______ Between $25,000 and $50,000/year
_______ Greater than $50,000/year

Part B: Bone Health

How long ago were you diagnosed with osteoporosis?
Years___________ Months__________

Have you had more than one vertebral fracture?
_______ No_______Yes If yes how many? _____

What was the score from your most recent BMD test?
____

Part C: Mobility

Have you fallen to the ground in the last year?
Yes _______ No _______

If yes, how many times have you fallen in the past year?
____

Have you ever broken a bone before?
Yes _______ No _________ (other than your spine)

If yes, which part of the body?
____
(If more than one please list)

Date of most recent fracture (any type):
____

Are you afraid of falling? Yes __________ No __________

If yes, explain why ___________________________________

Do you use any of the following for walking?

______Cane
______Walker
______Crutches
______Scooter
______Manual wheelchair
______Power wheelchair
______Other
____

What programs or services would you like to see in the community to help you manage your osteoporotic vertebral fracture?

Appendix E

Focus Group Protocol

Welcome group, Introductions, Letter of Information clarifications, Consent form and signatures, Completion of Demographic form, Overview of topic, Guidelines and ground rules, Start recording.

*Objective: What are your **needs for information, programs, or services** related to an osteoporotic vertebral fracture that can help you manage living independently in the community?*

Focus Group Questions

PART A

How do you live with an osteoporotic vertebral fracture?
How would you describe your quality of life?
What changes have you had to make? (compared to before your vertebral fracture)
What is the difference now?

Prompts:
Describe your daily routine.
Describe your leisure activities.
How osteoporosis/vertebral fractures influence your activities?
How do you adjust?

What things can make it easier to deal with challenges of living with osteoporosis and vertebral fractures?

What makes osteoporotic vertebral fractures different than other medical conditions?

PART B

Was there any information that you received after the vertebral fracture that you found helpful?

Did you look for information after your fracture? Where did you look?

How did you get information?

Is there any information you wished you had received?

PART C

What programs and/or services do you currently use in the community?
What makes it easy or difficult to use these programs/services?
What programs and services would you like to have in the community?

Appendix F

Poster recruiting participants

Western

Osteoporosis and Vertebral Fractures Focus Groups

You are invited to participate in a study that looks at the needs of people living with osteoporotic vertebral fractures for information, programs, and services.

We are looking for women age 65 and over who have vertebral fractures and live independently in the community.

If you are interested in participating, please contact **Liz Froats at:**

Thank you