Osteoporosis: Validity and reliability study of the Personalized Exercise

Questionnaire (PEQ)

# DEVELOPMENT, VALIDATION AND RELIABILITY OF THE PERSONALIZED EXERCISE QUESTIONNAIRE (PEQ) TO ASSESS EXERCISE FACILITATORS, BARRIERS AND PREFERENCES IN PEOPLE WITH OSTEOPENIA OR OSTEOPOROSIS

By: ISABEL RODRIGUES B.Sc.

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TITLE:Development, validation and reliability of the Personalized Exercise<br/>Questionnaire (PEQ) to assess exercise facilitators, barriers and<br/>preferences in people with osteopenia and osteoporosis

AUTHOR:	Isabel Rodrigues BSc (Honours).

SUPERVISOR:

Dr. Joy C. MacDermid.

Supervisory Committee:

Dr. Karen Beattie

Dr. Jonathan Adachi

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#### ABSTRACT

One in three women and one in five men will experience a fracture due to osteoporosis in their lifetime. The clinical significance of osteoporosis is largely due to increased fracture rates, particularly in the hip and spine, that may lead to immobility and subsequent hospitalization. This may increase the risk of cardiac complications, pneumonia and pulmonary embolism, significantly impacting in-hospital mortality. It is a major health issue, with an osteoporotic fracture occurring every 3 seconds worldwide. Exercise is often recommended for people with osteoporosis and has been shown to maintain bone mass and reduce falls with fewer side effects. Although exercise has multiple benefits, adherence to this activity is poor, with 50% of those registered in a program dropping out within the first 6 months. One method to increase adherence to exercise is to identify the facilitators, barriers and preferences to physical activity. Identification of these facilitators and barriers may allow researchers and clinicians to design better exercise programs that increase motivation. This dissertation discusses the development of a new tool that can measure the factors that affect exercise adherence and calculates the content and construct validity and the test-retest reliability of the measure in the osteoporosis population. This tool has potential applications in both the research setting and in clinical practice. Investigators can use this tool to survey their population of interest and use this information to leverage the facilitators and limit the barriers in their methodologies when designing activity programs, while clinicians can identify and design better exercise prescriptions for individual clients.

iv

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# Table of Contents

Chapter One: Overview of Osteopenia and Osteoporosis	1
1.1 Bone Structure	2
1.2 Pathophysiology of Osteoporosis	3
1.3 Clinical Manifestation, Epidemiology and Economics	4
1.4. Diagnosis and Risk Assessment	5
1.5 Management of osteoporosis	7
1.5.1 Drug therapies	7
1.5.2 Exercise therapies	8
1.6 Project Overview	8
1.7 Composition of Dissertation Papers	9
1.8 References	9
1.9 Appendix A.1	12
Chapter Two: Summary of a Systematic Review of Facilitators and Barriers	to
Exercise	13
2.0 Abstract	14
2.1 Background	14
2.2 Study Selection	15
2.3 Theoretical Framework	15
2.4 Study Characteristics	15
2.5 Facilitators and Barriers to exercise	16
2.6 Reported Adherence Rates	17
2.7 Conclusion	18
2.8 References.	18

2.9 Appendix A.2	19
Chapter Three: Development of the exercise questionnaire	23
3.0 Abstract	24
3.1 Background	26
3.2 Methods	26
3.2.1 Step One: Instrument Design	27
3.2.1.1 Content and Domain Specification & Item Generation	27
3.2.1.2 Instrument Construction	
3.2.2 Step Two: Judgmental Evidence (content validity)	
3.2.2.1 Content Validity	28
3.2.2.2 Cognitive Interviews	29
3.2.2.3 Focus Group	
3.3 Results	31
3.3.1 Content Validity Results	31
3.3.2 Questionnaire Refinement Result	33
3.4 Discussion	
3.5 Limitations	
3.6 Conclusion	
3.7 References	39
3.8 Appendix A.3	42
3.9 Appendix B.3	44
Chapter Four: Validation and Reliability of the PEQ	53
4.0 Abstract	54
4.1 Background	54

4.2 Methods	56
4.2.1 Ethics	56
4.2.2 Development of the PEQ	56
4.2.3 Measurement Properties	56
4.2.4 Participants	58
4.2.5 Study Design	58
4.3 Results	59
4.3.1 Descriptive Characteristics	
4.3.2 Dimensionality	60
4.3.3 Known-group Validity	61
4.3.4 Test-Retest Reliability	
4.4 Discussion	63
4.5 Strengths and Limitations	68
4.6 Conclusion	68
4.7 References	69
4.8 Appendix A.4	70
Chapter Five: Future Direction and Concluding Remarks	72
5.1 Summary	73
5.2 Study Strengths and Limitations	73
5.3 Future Directions	74
Appendix A: The Personalized Exercise Questionnaire (PEQ)	
Appendix B: Demographic Survey	84
Appendix C: Participants Information Sheet	85

## LIST OF ABBREVIATIONS

BMD	Bone Mineral Density
CAROC	Canadian Association of Radiologists and Osteoporosis Canada
CPG	Clinical Practice Guidelines
CVI	Content Validity Index
CVR	Content Validity Ratio
DXA	Dual Energy X-ray Absorptiometry
EBBS	Exercise Benefits/Barriers Scale
FRAX	Fracture risk assessment tool
HiREB	Hamilton Integrated Research Ethics Board
I-CVI	Item Content Validity Index
OA	Osteoarthritis
OPG	Osteoprotegerin
PEQ	Personalized Exercise Questionnaire
RANKL	Receptor activator nuclear factor ${K}$ B Ligand
S-CVI	Scale Level Content Validity Index
S-CVI/UA	Scale Level Content Validity Index/Universal Agreement
S-CVI/Ave	Scale Level Content Validity Index/Average
SD	Standard Deviation
SES	Socioeconomic Status

# List of Figures, Tables and Forms

## Figures:

Figure 1.1: Bone Remodeling Pathway	12
Figure 2.1: The TPB-SCT Model	19
Tables:	
Table 2.1: Reported Facilitators and Barriers to exercise in people with osteoporosis.	19
Table 2.2: Participation rates for the intervention group(s)	19
Table 3.1: Iterative Summary of changes to the PEQ.	44
Table 3.2: Calculations of the I-CVI for relevancy and clarity of each item	44
Table 3.3: Kappa score for relevancy of each item	46
Table 3.4: Calculating of CVR for the PEQ	47
Table 4.1: General demographic characteristics of participants that completed the PEQ.	59
Table 4.2: Exploratory Factor Analysis.	60
Table 4.3: Chi Square values and effect size for known-group      validity.	61
Table 4.4: Cohen's Kappa calculations	61
Table 4.5: Linear weighted Kappa calculations	62
Forms:	
Critical appraisal of the checklist of facilitators and barriers to exercise form	42
The Personalize Exercise Questionnaire (PEQ)	76
Demographic Survey	84
Participant Information Sheet.	85

## **DECLARATION OF ACADEMIC ACHIEVEMENT**

The Master of Science candidate, Isabel Rodrigues, is the primary author and lead contributor of this thesis. From September 2015 to July 2017, she was responsible for completing a systematic review for an independent study course, study protocol, ethics approval, recruiting participants, providing informed consent, data collection, data analysis and interpretation of data as well as the drafting of the manuscripts and incorporating feedback. Isabel Rodrigues was also responsible for developing the design and layout of the PEQ. Dr. Joy C. MacDermid, the thesis supervisor who provided funding for the project, was responsible for reviewing and refining of the research question and the PEQ, study design and manuscript revisions. Dr. Jonathan Adachi and Dr. Karen Beattie, who served as the remaining members of the supervisory committee, offered guidance and support, provided feedback during the committee meetings on the development of the PEQ and reviewed all manuscripts. Dr. Adachi also assisted in participant recruitment at his clinic.

Chapter One: Overview of Osteopenia and Osteoporosis

# Introduction to Osteoporosis, Clinical Evaluations and Treatments 1.1 BONE STRUCTURE

Bone is a porous mineralized structure composed of living tissues, such as cells and vessels, and crystals of calcium compounds (hydroxyapatite) (1,2). There are two main types of bones in a healthy, mature human skeleton: the cortical bone and the trabecular bone. Cortical bone, the outer shell of all bones, comprises 80% of the skeleton and is dense and compact, resulting in a slow turnover rate and high resistance to bending and torsion (1,2). Trabecular bone, surrounded by the harder cortical bone, comprises 20% of the skeletal mass, is less dense, more elastic and has a higher turnover rate than cortical bone (1,2). Trabecular bone is continuously remodeled during adulthood through resorption of old bone by osteoclasts and the formation of new bone by osteoblasts. Cortical bone is also remodeled but at a much slower rate. These two events are closely coupled together and are responsible for renewing the skeleton.

There are three main types of cells that make up the bone: osteoclasts, osteoblasts and osteocytes. Osteoclasts arise from granulocyte-macrophages cells and are responsible to remove bone (resorption), while osteoblasts ascend from fibroblasts cells and form bone (formation) (3). Systemic hormones, such as parathyroid hormone and 1,25-dihyroxyvitamin  $D_3$ , and local factors, such as interleukin-1 and tumor necrosis factor, promote the development of osteoclasts and osteoblasts cells (3). These two cells closely collaborate in the remodeling circular process; during a cycle, 10 osteoclasts dig a circular tunnel in the dominant loading direction and, subsequently, this tunnel is filled by several thousands of osteoblasts (1). Osteocytes are derived from osteoblasts and make up over 90% of the cells in the bone. At the end of bone formation, osteoblasts can either become embedded in bone as osteocytes, become inactive osteoblasts, become bone-lining cells or undergo apoptosis. Deeply embedded osteocytes express high levels of a protein called sclerostin, expressed by the SOST gene, which is a negative regulator of bone formation. Mutations of the SOST gene cause high bone mass in humans and deletion results in high bone mass in mice.

When bone is formed in an unborn child, the majority of the skeleton is made up of cartilage that eventually gets replaced by true bone after birth (2). Throughout childhood and adolescence bones grow to become longer, denser and stronger. By the time most people reach their 20s, their bones have stopped growing and by 30, have reached maximum bone density. Before the age of 30 osteoblast activity is greater

than osteoclasts activity, however after the late thirties bone formation no longer keeps up with bone removal (2). After the age of 40, bone resorption exceeds bone formation resulting in decreased bone density. When bone resorption exceeds bone formation to the point where 25% of bone mass is lost compared to the bone mass of an average 30 year old person, this is called osteoporosis (2).

#### **1.2 PATHOPHYSIOLOGY OF OSTEOPOROSIS**

Osteoporosis is defined as a skeletal condition characterized by reduced bone mass and microarchitectural deterioration of bone tissue, which may increase the risk of fractures (4). Bone mass can be measured through bone mineral density (BMD). Once peak bone mass is reached, the distribution of bone mineral content follows a Gaussian (normal) distribution, and due to this normal distribution bone density values can be expressed in standard deviations (SD) (5). A BMD value between 1 and 2.5 SD below the mean value for young adults is referred to as osteopenia while a BMD more than 2.5 SD below is called osteoporosis (6). The pathogenesis of osteoporosis involves a number of factors including genetics, systemic hormones, inflammatory cytokines, the immune system, growth factors, collagen abnormalities, nutrition, exercise, lifestyle choices, and medications (4,7,8).

One of the most studied factors that lead to the development of osteoporosis is estrogen deficiency. Osteoblasts and osteoclasts express estrogen receptors which bind estrogen leading to upregulation of osteoprotegerin (OPG) and blocks the upregulation of receptor activator nuclear factor  $-_{K}B$  Ligand (RANKL) (7). OPG is a competitive inhibitor of RANKL and antagonizes the actions of RANKL (Figure 1.1). OPG is a protein that decreases the process of bone loss and helps maintain a balance between bone resorption and formation while RANKL is a protein that stimulates the growth of osteoclasts (9). The above mechanism is a simplified explanation; there are a number of steps involved in the OPG/RANKL pathway that lead to low bone mass and are beyond the scope of this paper. In postmenopausal women estrogen deficiency directly decreases the OPG protein and indirectly increases RANKL. Subsequently, this leads to higher levels of osteoclast generation and ultimately bone loss (2,7). Similarly in men, decline in the male hormone testosterone due to age can also play a role in the development of osteoporosis. Decline in the testosterone hormone is gradual unlike the rapid decline of estrogen in females after menopause and is referred to as "andropause" or "androgen deficiency in the aging male" (2). Testosterone plays a major

effect on preosteoblasts, directly causing them to differentiate into mature osteoblasts (10,11). Testosterone can also be converted to estrogen via the aromatase enzyme and, in men, follows the same pathway as described above (10). Thus the major cause of osteoporosis in women is estrogen deficiency due to menopause, while in men it is age-related testosterone deficiency (11). Other factors such as nutrition can also affect bone loss; decreased calcium intake can decrease intestinal calcium absorption and subsequently increase parathyroid hormone release and activate RANKL. In addition, aging is also a risk factor to osteoporosis since peak bone mass naturally declines with age after the mid thirties (12).

#### **1.3 CLINICAL MANIFESTATION, EPIDEMIOLOGY AND ECONOMICS**

Osteoporosis is a silent disease common in both men and women and diagnosis either occurs during an assessment with a physician or when a fragility fracture occurs (8). Fragility fractures occur with minimal trauma, such as falling from standing height, and may result in mortality, morbidity, chronic pain and high economic costs (13). It is estimated that 9.9 million Americans have osteoporosis and 43.1 million low bone density, and, similarly, 1.5 million Canadians 40 years and older have been diagnosed with osteoporosis (14). About one in two Caucasian women and one in five Caucasian men will experience an osteoporosis-related fracture in some point in their life (14). Both fractures of the hip and vertebrae are hallmarks of osteoporosis (15). Fractures of the hip are one of the most harmful types of osteoporotic fractures since almost 20% of patients die during the first year from this type of fracture and those that survive, one third require nursing home placement after discharge (8). Similarly, vertebral fractures are also associated with increased morbidity and can result in possible mortality. Multiple thoracic fractures can result in restrictive lung disease, progressive back pain and disabling kyphosis and this pain can have damaging psychological effects with serious negative consequences (8).

Osteoporotic fractures are a major public health burden worldwide, but fracture rates vary greatly across different racial groups (16). Bone strength can differ between different ethnic groups depending on a number of structural properties including the diameter of the bone, thickness and number of trabeculae and cortical thickness (17). Ethnicity and race are important factors that influence the incidence of osteoporosis (15). The prevalence of vertebral fractures in women 65 years and older is 70% for Caucasians, 68% for Japanese, 55% for Mexican, and 50% for African American women (15). After adjusting for body weight and height, African American women have the highest BMD followed by Hispanic women. Asians, Native

Americans and Caucasians have similar and the lowest BMD values (17). Despite having similar or lower BMD, Asian-American women have fewer non-vertebral fractures than Caucasian women (18). This paradox is partly explained by the differences in the hip geometry of Asians, which can support greater resistance to compressive and buckling forces (16). In additional the orientation of the trabecular bone is more axially aligned and they have more plate-like trabecular bone that is about 18% denser compared to Caucasians. Although African Americans have the highest BMD levels and Asian Americans the lowest, these two groups have the same low risk of fracture (17).

The cost of osteoporosis in 2010 was around 2.3 billion Canadian dollars, which accounts for 1.3% of the healthcare expenditure in Canada (19). Costs were due to osteoporosis-related hospitalizations, emergency care, surgeries, rehabilitations, long-term care, physician visits and prescription drugs (19). Fractures caused by osteoporosis are more common than heart attack, stroke and breast cancer combined and consume more hospital bed days than stroke, diabetes or heart attack (20). At least one third of women and one fifth of men will suffer from an osteoporotic fracture in their lifetime, but despite the high prevalence of fragility fractures in the Canadian population fewer than 20% of women and 10% of men received therapy to prevent future fractures (13,20).

#### 1.4 DIAGNOSIS AND RISK ASSESSMENT

Current clinical practice guidelines regarding the diagnosis and management of osteoporosis suggest individuals, both male and female, over the age of 50 be assessed for risk factors associated with osteoporosis and factors associated with high risk of fracturing. Some risk factors include measuring height annually, assessing for the presence of vertebral fracture, evaluating fall history in the past year and doing blood work (13). But the most accurate way to diagnose osteoporosis is by using an instrument to measure bone density (21).

A number of tools exist to measure bone mineral content and fracture risk including: radiography, dual Energy X-ray absorptiometry (DXA), ultrasound and computed tomography (5). Radiography works by emitting X-ray beams that pass through the bones and by detecting what is not absorbed (22,23). The denser the bone, more X-ray energy is absorbed, while less dense and more porous areas absorb less energy. A "picture element", the radiation energy per pixel, is created and then converted into an "areal

density value" measured in grams/centimeter (g/cm) (22). The problem with simple radiography is that it produces low sensitivity images that may not accurately diagnose osteoporosis (5). Similarly, DXA works by emitting two X-ray beams of different energies (dual X-ray absorptiometry) and values can be quoted in g/cm<sup>2</sup>, which are then converted to a T-score or Z-score using the following formula:

$$T = \frac{patient's BMD-population BMD}{standard deviation of the population peak BMD}$$

$$Z = \frac{patient's BMD-population age related BMD}{standard deviation of population age-related BMD}$$

DXA is currently regarded as a gold standard for the diagnosis of osteoporosis and the accuracy of DXA at the hip exceeds 90% (5). Although ultrasonic measurements cannot be used to diagnose osteoporosis it lends support for the assessment of fracture risk in elderly women (5). Computed tomography can be used to diagnose osteoporosis, but the scanner needs to be calibrated to convert the results into units relevant to BMD. This technique is also not very useful in practice due to high exposure to radiation, high cost and difficulties with quality control compared to DXA (5).

For women, there are four general diagnostic categories proposed by the WHO for the assessments done with DXA:

- Normal hip BMD T-score greater than 1 SD below the young adult female reference mean (T-score ≥ -1.00 SD);
- Osteopenia hip BMD T-score less than -1.00 SD below the young adult female reference mean but greater than -2.5 SD;
- Osteoporosis hip BMD T-score less than -2.5 SD below the young adult female reference mean;
- Severe osteoporosis hip BMD T-score less than -2.5 SD below the young adult female reference mean and the presence of one or more fragility fractures

The cutoff values for men are less defined than for women, but a number of studies have indicated that similar cutoff values for the hip BMD for women can be used to diagnoses osteoporosis in men (5).

Canadian guidelines also suggest evaluating risk of fracture in people diagnosed with osteoporosis and this can be assessed using: 1) the WHO's fracture risk assessment tool (FRAX) or 2) the Canadian Association of Radiologists and Osteoporosis Canada (CAROC). These risk assessment tools categorize

participants as having low, moderate or high risk of fracturing over a period of 10 years, and physicians can then use this information to prescribe the proper medications (24). Risk factors measured by FRAX include age, sex, weight, height, previous fragility fracture of the hip, smoking status, use of glucocorticoids, history of rheumatoid arthritis or secondary osteoporosis, alcohol intake and BMD of the femoral neck (24,25). CAROC uses a graph/chart for women and a different one for men and uses age, sex and hip BMD to identify preliminary fracture risk. Individuals that have a fragility fracture or are currently using steroid medication (e.g. prednisone) are moved up by one risk level (24,25). Although CAROC may be less comprehensive than FRAX, the results are similar regardless of the tool used (25). Based on a patient's risk of fracture assessment, physicians will know which pharmacological treatment plan is the most appropriate for their patients since some osteoporosis medications can reduce the risk of fractures by 40% to 70% (24).

#### **1.5 MANAGEMENT OF OSTEOPOROSIS**

#### **1.5.1 Pharmacological therapies:**

Several effective drug treatments for osteoporosis have become widely available during the past decade and include antiresorptive agents, such as bisphosphonates, denosumab, calcitonin and raloxifene, and bone-forming agents, such as teriparatide (13). Bisphosphonates are the gold standard of antiresorptive drugs and they bind to hydroxyapatite crystals with high affinity to create the hydroxyapatite/ bisphosphonate complex. This complex is then phagocytosed by osteoclasts during the resorption phase and the bisphosphonate that was also engulfed sets off a reaction that ultimately leads to the apoptosis of that osteoclast cell (9). Bisphosphonates only reduce the number of osteoclasts and play no role in increasing osteoblast activity. Denosumab, on the other hand, does reduce the risk of fracturing since it is a monoclonal antibody that binds with high affinity and specificity to the RANKL, preventing it from binding to RANK and inhibiting osteoclast differentiation while allowing OPG to bind and activate osteoblast cells. Denosumab plays an important role in both the trabecular and compact bone (9). In additional to prescription pharmacological therapy, Osteoporosis Canada also recommends routine calcium and vitamin D supplementation.

#### **1.5.2 Exercise therapies**

Before 2002, the goal of physicians and other healthcare providers was to treat low BMD, but in the last decade a paradigm shift has focused on prevention of fragility fractures and their negative

7

consequences (13). National and international organizations thus emphasize, in addition to pharmacological therapy, the importance of exercise and physical activity for the prevention of bone loss, fractures and falls (26). A number of systematic reviews have shown weight bearing exercise can maintain and even increase BMD in the spine and hip in postmenopausal women and reduce falls in older adults by almost 40% (27–30). In addition, two meta-analyses have provided strong evidence that exercise reduces the risk of falls in older adults (26).

Weight bearing exercises increase mechanical load on the skeletal system by creating strain on the bones and improve bone quality. Cells such as osteocytes contain mechanoreceptors that sense this strain and activate the Wnt- $\beta$ -catenin canonical signalling pathway and trigger the bone remodelling process by directing osteoblastic activity and osteoclastic resorption (37). Exercise also has a direct influence on the skeleton by directly improving muscle mass and strength and induces changes at the hormonal level by influencing levels of circulating Growth Hormone and Insulin-like Growth Factor, which exert anabolic effects on muscle and bone (37).

#### **1.6 PROJECT OVERVIEW**

The problem with exercise is that adherence to physical activity is poor, with 50% of those registered in an exercise program dropping out within the first 6 months (31). A number of articles suggest identifying the facilitators and barriers to exercise as one method to improve exercise adherence (32–34). One approach to identify these motivators, barriers and preferences to exercise is through a questionnaire or survey. Questionnaires are the most frequently used method of data collection in the field of Rehabilitation Science and the most feasible option to survey large populations (35). Self-reported measures have gained substantial support due to a number of recognized benefits that include lower costs, ease of administration, and simplicity to analyze raw data. A growing body of literature has examined levels of physical activity among different populations using self-reported questionnaires (36) and there is an increased interest to integrate patient-reported outcomes into clinical practice. Given that physical inactivity is a leading risk factor for mortality, it has become essential for healthcare providers and investigators to identify factors that increase adherence to exercise programs. Patients' self-reported measures have potential to improve patient-clinician communication and the quality of interventions. Thus, the most feasible and economic

method to increase exercise adherence is to identify the facilitators, barriers and preferences to exercise using self-reported measures. Currently no questionnaire exist that measure these factors, hence this master's thesis will describe the steps on the development of a new tool that measures factors that affect adherence and report the validity and reliability of this assessment in the osteoporosis population.

#### **1.7 COMPOSITION OF DISSERTATION PAPERS**

This dissertation is compromised of three papers, chapters two to four. These papers include the results of a summary of a systematic review, the development of the self-report measure and the validity and the reliability of the measure as part of the requirements for the master's program in the School of Rehabilitation Sciences at McMaster University.

The systematic review paper of randomized control trials (Chapter 2) provides a summary of the most common facilitators and barriers to exercise reported in the osteoporosis population. The next study (Chapter 3) describes the developmental process and the content validity of a new questionnaire, the Personalized Exercise Questionnaire (PEQ), which identifies the facilitators, barriers and preferences to physical activity in people with osteoporosis. The last research paper (Chapter 4), establishes the construct validity and the test-retest reliability of the PEQ in this population.

In summary, research in this dissertation attempts to provide one method to increase exercise adherence in the osteoporosis population by developing a novel tool that assess the facilitators, barriers and preferences to exercise.

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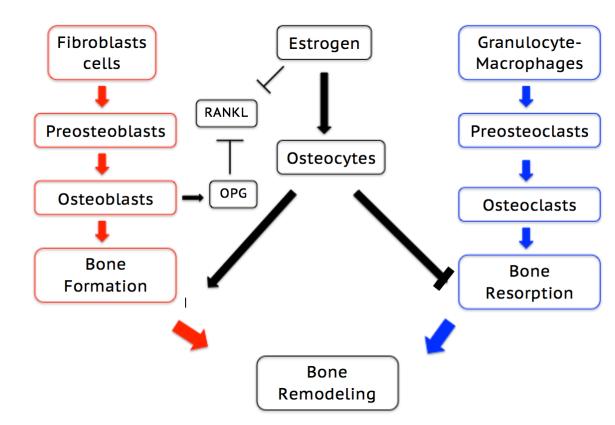
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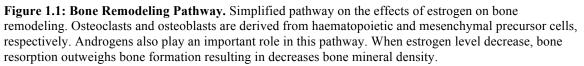
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## **1.9 APPENDIX A.1**



# Chapter Two: Summary of a Systematic Review on the Facilitators and Barriers to Exercise

#### Facilitators and barriers to exercise in patients with osteopenia and osteoporosis

#### 2.0 ABSTRACT

Several studies have shown exercise to be successful in maintaining or increasing BMD in individuals with low bone mass. Yet, adherence to exercise is poor, with 50% of those registered in an exercise program dropping out within the first 6 months, lack of time being the number one barrier in many populations (1,2). Identifying the facilitators and barriers to exercise may be one method to identify major obstacles to adherence in the osteoporosis population. Recently, a systematic review published in the journal Osteoporosis International has listed the main facilitators and barriers to physical activity in this group (3).

Fifty-four randomized control trials (RCTs) examined exercise interventions in patients with osteopenia or osteoporosis and found a spectrum of facilitators and barriers to exercise. No one facilitator was more frequently reported than the other and the most commonly reported barriers were lack of time and transportation (3). In most RCTs, methods to promote and measure exercise adherence were unsatisfactory. Of the 54 papers, 72% reported an adherence rate to an exercise program; the lowest reported rate was 25%, and the highest 100% (3).

#### 2.1 BACKGROUND

Several studies suggest that barriers to exercise may hinder the adoption and maintenance of regular participation in an exercise program (1,4,5). This creates difficulty not only for investigators running the exercise intervention but also to the patients who would otherwise receive health benefits from such programs. To increase exercise adherence, interventions must leverage the facilitators and limit the barriers to exercise (6,7). Identification of these facilitators and barriers may allow researchers to test strategies to increase motivation and adherence that can be applied in practice. To our knowledge, there is only one systematic review that identified the facilitators and barriers to exercise in the osteoporosis population (3). The primary purpose of this chapter will be to summarize this systematic review and report the facilitators and barriers to exercise adherence in people with osteopenia or osteoporosis.

#### 2.2 STUDY SELECTION

Fifty-four RCTs examining exercise interventions in patients with osteopenia or osteoporosis were included (3). The following information was extracted from the papers: year of publication, duration of the exercise intervention, outcome measurements utilized, intervention cost for the participants, exercise instructor's qualification, age and number of participants, average BMD T-score, location/type of exercise facility, number of falls occurring during the intervention, methods to promote exercise adherence, methods to measure adherence, drop-out rates, adherence rates to exercise, barriers and facilitators to the exercise program, methodological quality score and the study's country of origin. The socioeconomic status (SES) of the participants and their views about the exercise program were not available in any of the RCTs (3).

#### **2.3 THEORETICAL FRAMEWORK**

To address the facilitators and barriers to exercise a theoretical framework was used to assist with the identification and categorization of these outcomes (8). In the last decade, the use of theory has received wide recognition due to its ability to provide a more meaningful contribution to understanding health issues (8). This paper used the components, "perceived behavioural control", "attitude toward the behaviour", and "normative beliefs", from the Theory of Planned Behaviour and, the "environment", from the Social Cognitive Theory as a guide to categorize the facilitators and barriers to exercise (Figure 2.1 in Appendix A.2).

#### **2.4 STUDY CHARACTERISTICS**

Most study participants were women 50 years of age and older and had a T-score between -1.0 and -2.5. Only 17 papers enrolled patients with a T-score of -2.5 or lower. Of all included studies, the youngest registered participants in the intervention group had an average age of 45.5 (SD 9.6) and the oldest 79.6 (SD 2.1). Identified studies originated from a number of countries including: Australia, Belgium, Brazil, Canada, Finland, Germany, India, Italy, Japan, Kosovo, Netherlands, Norway, Poland, Sweden, Taiwan, Turkey, and the U.S.A.

Within the 54 included RCTs, there were 26 different types of exercise interventions studied in patients with osteoporosis. Ten papers studied balance related exercises, eight resistance training, six Tai Chi, three circuit training, three home-based exercises, three aquatic exercises, two high or low impact

training and the remaining nineteen studies were so distinct from one another they could not be categorized. Exercise program duration varied, with the shortest being 8 weeks and the longest 30 months. The average length of an exercise program was close to 6 months. Only six out of the 54 papers mentioned the cost of the intervention and no paper discussed the socioeconomic status of its participants. High variability among exercise programs was also identified in this review. Information regarding exercise dosage and type varied and rationale to support a specific type of exercise was poorly supported. None of the included papers clearly justified exercise dosage choice or referenced the WHO exercise guidelines, which may explain the variation among studies. The most common reason for selecting an exercise intervention in each paper was based on whether that exercise had or had not been previously examined.

#### 2.5 FACILITATORS AND BARRIERS TO EXERCISE

Of the included papers, only 26% mentioned facilitators to exercise adherence and 62% reported barriers to exercise adherence. There were a number of facilitators identified, however, no one single facilitator was more commonly reported than the other. A dichotomy may be occurring since factors that facilitate may be the reverse of those acting as a barrier or vice versa (i.e. the most common environmental barrier to exercise was a lack of time and the environmental facilitator was a flexible program schedule). Overall, the motivators identified in this review were similar to those in other populations (i.e. osteoarthritis and older adult populations). The largest barriers to exercise for people with osteoporosis were transportation to the exercise facility and a reported lack of time to adhere to the program. Similar studies on barriers to exercise found participants reported lack of time as a major barrier; this has been shown to be true in many populations, not only for patients with osteopenia or osteoporosis (1.2). However, it is not clear whether this barrier reflects an actual lack of time or a perceived lack of time. Future work is required in order to determine to what extent patients' perceptions are in line with reality, or if other underlying factors are causing patients to perceive lack of time as a barrier. If this barrier is in fact accurate, methods such as time management classes to assist participants with integrating exercise into a busy schedule may be necessary. However, if patients' perceived lack of time does not reflect an actual lack of time, qualitative studies, to determine the underlying ideas and factors causing this misconception in patients should be evaluated. Table 2.1 in Appendix A.2 summarizes the facilitators and barriers to exercise adherence reported in the RCTs (3).

16

#### 2.6 REPORTED AHDERENCE RATES

Few papers discussed means to measure and promote exercise adherence. Of the included studies, 72% reported adherence rates to the exercise program, however only 3 papers discussed how they actually measured adherence rates. Methods used to measure and promote adherence included: taking attendance every session, telephone calls every three weeks, exercise diaries that were checked every three months by a physiotherapist and sending quarterly newsletters. Studies that used these methods to measure adherence varied in participation rates from 51.7% to 97.5%. The Circuit study had the lowest adherence rate (25%) and the JUMP trial and the home exercise program had the highest adherence rate (100%). The Circuit study provided no information about dropout rates or facilitators and barriers to exercise. Although this program was only 3 months and supervised by a physiotherapist, it is possible that other factors could have influenced participation. The average age of the patients was 70.8 years so barriers such as transportation, poor health and not liking the exercise (i.e. circuit training) could explain the lower adherence rate. The Thoracic Spine Rehabilitation study also had a low rate of adherence (51.7%), despite using methods such as telephone calls every three weeks to promote continuous attendance, and in this case reported barriers found the majority of participants had financial or mobility problems that may have interfered with their ability to continue the exercise program. Other reported barriers in this study were: believing physical therapy was unnecessary, feeling too old to participate, discouraged by the physician and afraid to exercise. Thus, methods to promote adherence to exercise may be more efficient if they focus on limiting the barriers and concurrently encourage participants through telephone calls, logbooks or newsletters (3). The JUMP trial reported 100% participation, but this study did not report a true adherence rate since 15 participants (26%) voluntarily dropped out after the study became active due to time barriers, medical restrictions, change in employment and relocating to a new area. The home-based program also had a perfect participation rate and was measured using the participants' word. Facilitators of the home-based program included easy to perform and to remember exercises.

The length of the exercise intervention did not seem to affect adherence rates and participation rates were generally higher in supervised programs. A large variability in exercise participation exists in the osteoporosis physical activity literature. Even though methods to increase exercise were implemented in three studies, two papers still reported an adherence rate of less than 80%. One third of papers that reported

17

participation rates had an adherence of less than 70%. It is also difficult to estimate the average adherence rate of all these RCTs since the values were not based on a uniform criterion.

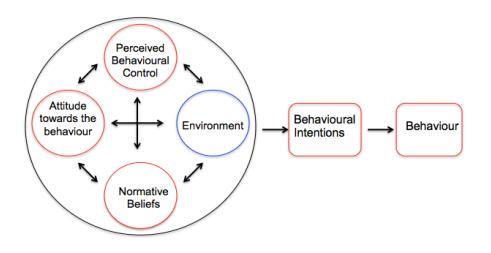
### **2.7 CONCLUSION**

In this review, the most common barriers to exercise in the osteoporosis population were: lack of time and transportation. A number of facilitators were identified including flexible workout schedules and modified exercise plans but no facilitator was more common than the other. Methods to promote and measure exercise adherence were poorly reported in most papers and a large variability in exercise type and dosage was found.

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## 2.9 APPENDIX A.2



**Figure 2.1:** The TPB-SCT Model. This figure illustrates a linear diagram with four interdependent elements of perceived behavioural control, attitudes toward the behaviour, environment, and normative beliefs, which together influence behavioural intentions and ultimately behaviour. Environment is assumed to be one of the components that effects behavioural intentions. The red colour represents components from the TPB, and the blue colour from the SCT.

Facilitators	Barriers
<ul> <li>Perceived Behavioural Control</li> <li>No facilitators were identified for this section</li> <li>Attitude Toward Behavior</li> <li>Less pain</li> <li>Less fatigue</li> <li>Able to walk longer</li> </ul>	<ul> <li>Perceived Behavioural Control</li> <li>Fear of falling or injury</li> <li>Afraid of exercise</li> <li>Attitude Toward Behavior</li> <li>Lack of interest</li> <li>Physical activity unnecessary</li> <li>Too old to participate</li> </ul>
<ul><li>More flexible</li><li>Reduced number of falls</li></ul>	
<ul> <li>Environment</li> <li>Flexible program times (sessions offered several different times every day of the week)</li> <li>Modification to exercise plan to account for pain in the knees, hip or back</li> <li>Home based exercises to eliminate transportation and high fees</li> <li>Location in a secure, pleasant or natural environment</li> </ul>	<ul> <li>Environment</li> <li>Lack of time</li> <li>Transportation</li> <li>Medical conditions</li> <li>Mobility problems (i.e. using a walker)</li> <li>Lack of finances</li> <li>Language barrier</li> <li>Chlorine allergy/rash</li> </ul>

 Table 2.1: Reported facilitators and barriers to exercise in people with osteoporosis

<ul> <li>Opportunity for social interactions</li> <li>Exercises easy to perform, to remember and enjoyable</li> <li>Small exercise group (n&lt;10)</li> </ul>	<ul> <li>Travelling, moving location or life transition</li> <li>Family priorities</li> <li>Inconvenient exercise/class time</li> </ul>
<ul> <li>Normative Beliefs</li> <li>Physical therapist with a positive attitude toward exercise</li> <li>Under supervision of a physiotherapist or a healthcare professional</li> </ul>	<ul><li>Normative Beliefs</li><li>Discouraged by physician</li></ul>

Intervention	Duration of the program	Age / # of participants	Reported Adherence rate of intervention group(s) (not including controls)
Aquatic vs. Land Exercise	20 weeks; 3 x/ week; 50 mins each session	Aquatic: $68.6 \pm 5.4/31$ Land: $69.1 \pm 6.3/33$ Control: $67.7 \pm 6.3/27$	68%
High impact exercise	6 months; 3 x/week; 60 mins each session	Strengthening:55.9±4.9/14 High-Impact:55.6±2.9/14 Control:56.2±4.0/14	80%
Thoracic Spine Rehabilitation	3 months; 18 sessions; 15-20 mins per session	Rehab: 75.2 ± 1.3/29 Control: 77.6 ± 1.6/19	51.5%
Circuit exercise	3 months; 2 x / week; 1 hour per session	Intervention: $70.8 \pm 5.9/47$ ; Control: $72.0 \pm 5.8/42$	25%
Physical training included fast walks, exercises for arms, legs, back and stomach, aerobic exercises and stretching	12 months; 1 x / week; 2.5 hours per session	Training: 58.9 ± 4.3/48 Control: 59.6 ± 3.6/44	95%
Training (resistance training, impact loading and balance exercises)	12 months; 3 x/week; 60 min per session; 2 one week scheduled breaks	Training: 60.3 ± 5.6 /19 Control: 56.3 ± 4.7 /20	78%
Physical training(flexibility training, rapid walking, aerobic dancing and stepping up and down from benches)	12 months; 3x / week; 1 hour per session	Exercise: $59.6 \pm 5.82/61$ ; Control: $59.9 \pm 6.36/63$	73%
Posture exercises (exercises for balance and improvement of muscular strength of the lower limbs)	8 weeks; 2 x / week; 1 hour per session	Exercise: 72.8 ± 3.6/17; Control: 74.4 ± 3.7/16	82%
Physical exercise (include balance and improvement of muscular strength of the lower limbs (strengthening) or exercises for balance and improvement of muscular flexibility (stretching))	8 weeks; 2 x / week; 1 hour per session	Strengthening: $72.8 \pm 3.6/17$ Stretching: $72.17 \pm 2.65/18$ Control: $74.4 \pm 3.7/16$	78%
Osteofit: Strength and balance program	10 weeks; 2 x/ week; 40 mins per session	Exercise: $71.6 \pm 3.9/45$ Control: $70.8 \pm 4.0/48$	44%
Osteofit: Figure eight circuit exercise	20 weeks; 40 mins per session	Exercise: $69.6 \pm 3.0/45$ Control: $69.0 \pm 3.5/48$	89%
Exercise (flexibility, stretching and calisthenics and aerobic exercises like walking, dancing and stepping)	24 weeks; 3 x/week; 60 mins per session	Exercise: 55.64±6.44/44; Control: 53.33±3.96/30	92%
Exercise (flexibility, stretching and calisthenics and aerobic exercises like walking, dancing and stepping)	24 weeks; 3 x/week; 60 mins per session	Exercise: 55.64±6.44/44; Control: 53.33±3.96/30	92%
Tai Chi	24 weeks; 3 x/week;	Tai Chi: $72.4 \pm 6.2/40$ ; Control: $71.3 \pm 6.0/41$	94%

## Table 2.2: Participation rates for the intervention group(s)

	60 mins per session		
Water-based exercise (warm-up, stretches, aerobic, Tai Chi, strength, posture, gait, vestibular, proprioception, and balance activities)	10 weeks;2 x/week;60 mins per session	Water-based: Not specified /25; Control: Not specified /25	80%
OsteoACTIVE (adapted from OsteoFit)	6 months; 3 x/week; 60 mins per session	OsteoACTIVE: 65.5 ± 7.1/42; Control: 63.9 ± 7.1/38	48%
Balance training program (i.e. walking/standing/sitting on uneven surfaces, eyes open/closed)	12 weeks; 3 x/week; 45 mins per session	Training: 76 (67–86)/34; Training+exercise:76 (67– 87) /31; Control:75 (66–84) /31	66%
Resistance training verse jumping training (called JUMP)	12 months; 2 x/week (resistance); 36 mins per day (resistance); 3 x/week (JUMP); 54 mins per day (JUMP)	Resistance:45.5 ± 9.6/19 Jumping: 42.1 ± 10.6 /19	100%
Balance training and weight-bearing exercises	20 weeks; 2 x/week; 60 mins per session	Exercisers: 61.5 ± 8.2/50; Control: 61.9 ± 9.6/ 48	70%
Resistance training at the center and home	24 months: Center: 2 months; 2 x/week and then; 3rd and 4th moth; 1 x/week 5th and 6th month; ever 2 weeks; 7-24 months; 1 class and 1 telephone call per month OR 2 classes per month; Classes were 1 hour per session Home:	Upper training: $67.8 \pm 4.6/78$ Lower training: $67.2 \pm 4.9/75$	25.7%
Exercises to train muscles of the upper and lower extremities, abdominal muscles and back extensor muscles	45 mins 1 year; not clear	Intervention: 74.7 ± 6.7/37; Control: 74.3 ± 7.0/32	97.5 %
Balance, Leg strength and impact training session	30 month (Total); 6 months x 2 (October to March); 6 months x 2 (April to September)	Exercise: 72.7 ± 1.1/84; Control: 72.6 ± 1.2/76	82.1 %
Tai Chi + green tea polyphenols	24 weeks; 3 x/week; 60 mins per session	Placebo: $57.6 \pm 7.5 / 44$ ; Green Tea: $56.5 \pm 5.5 / 47$ ; Placebo + Tai Chi: $58.3 \pm 7.7 / 42$ ; Green tea + Tai Chi: $57.6 \pm 6.7 / 38$	83 %
Tai Chi + green tea polyphenols	24 weeks; 3 x/week; 60 mins per session	Placebo: $57.6 \pm 7.5 / 44$ ; Green Tea: $56.5 \pm 5.5 / 47$ ; Placebo + Tai Chi: $58.3 \pm 7.7 / 42$ ; Green tea + Tai Chi: $57.6 \pm 6.7 / 38$	83 %
Resistance and agility training (high intensity in nature)	13 weeks; 2 x/week; 50 mins per session	Resistance: $79.6 \pm 2.1/32$ ; Agility: $78.9 \pm 2.8/34$ ; Stretching: $79.5 \pm 3.2/32$	85 %
Resistance and agility training (high intensity in nature)	25 weeks; 2 x/week; 50 mins per session	Resistance: $79.6 \pm 2.1/32$ ; Agility: $78.9 \pm 2.8/34$ ; Stretching: $79.5 \pm 3.2/32$	85 %
Resistance and agility training (high intensity in nature)	25 weeks; 2 x/week; 50 mins per session	Resistance: $79.6 \pm 2.1/32$ ; Agility: $78.9 \pm 2.8/34$ ; Stretching: $79.5 \pm 3.2/32$	85 %
Balance training program at the club	12 months;	Balance: $74.57 \pm 4.82/34$ ;	60%

and at home	Club:	Control: 73.40 ± 4.61/32	
	1 x/week;		
	60 mins per session;		
	Home: 3 x/week;		
	30 mins per session		
	12 weeks;		
	3 x/week;		
	2 sets of 8-12 reps at 50%	Exercise: $61.9 \pm 5.0 / 8$ ;	
Squat exercise	participant's training load	Control: $66.7 \pm 7.4 / 8$	87%
	followed by 4 sets of 3-5	Control: 00.7 ± 7.470	
	repetitions at 85-90% of		
Rehabilitation program (Fast walking,	participant's training load 1 month;		
hip extensors, trunk extension, etc.)	3 x/week;	Exercise: $65.6 \pm 5.8/45$ ;	93%
verse educational training session	60 mins per session	Control: $65.6 \pm 5.3/45$	2370
Resistance training and	••• ••••• p •• •••••		
electromagnetic field pulses		Resistant training:/13;	
(exercises consisted of hip flexion/	18 session over 6 weeks;	Pulses:/12;	90%
abduction/extension, knee extension,	3 x/ week;	Resistance training +	
shoulder press, chest press, scapula	30-40 mins per session	pulse:/11;	
retraction, leg press, back extension,		Control:/12	
and squat) Home-based exercise program			
(combination of upper and lower	12 months;		
body activities using there bands for	3 x/week;	60 years and older	
strengthening and aerobics)	60 mins per session		77%
		Placebo: $57.6 \pm 7.5 / 44$ ;	
	6 months;	Green Tea: $56.5 \pm 5.5/47$ ;	
Tai Chi + green tea polyphenols	3 x/week;	Placebo + Tai Chi: $58.3 \pm$	
0 1 51	60 mins each session	7.7/42; Green tea + Tai Chi:57.6 ±	83%
		6.7/38	8370
	3 months;	Sling: $71.0 \pm 6.1/25$ ;	
Sling exercises vs. conventional	2 x/week;	Physiotherapy: $69.7 \pm$	88%
physiotherapy	30 mins per session	3.7/25	
	3 months;	Physical therapy: $66.17 \pm$	
Physical therapy	12 sessions	6.66/24;	58%
		Control: 67.13 ± 8.38/24	
Home exercise program (squeezing a	Not clear how many months; 3 x/ day;	Exercise: $64.2 \pm 9.6/9$ ;	100%
ball in one hand)	3 x/week;	Control: $57.6 \pm 15.4/7$	100/0
	20 squeezes each session	2011101.07.0 = 10.07	
	5.5 weeks;		
	11 sessions;	Exercisers : $70.5 \pm 5.0 / 50$ ;	
Nijmegen Falls Prevention Program	Each session varied in time	Control: 71.6 $\pm$ 4.4 /46	53.2%
	from minimum of 15 mins to		
Programing load training	a maximum of 90 mins		
Progressive load training (Warm-up on the treadmill followed			
by static stretching of the upper and			
lower limbs, lumbar, cervical and	18 weeks;	Exercise: $63.1 \pm 4.53/50$ ;	
thoracic region followed by	2 x/week;	Control: 62.78 ± 4.87/50	75%
functional exercises for			
proprioception and balance and lastly			
strengthening exercises of the legs)			
LIFTMOR (Lifting Intervention For	9 months:		
Training Muscle and Osteoporosis Rehabilitation) vs. low-load home	8 months; 2 x / week;	LIFTMOR: 65.3±3.9/36;	87.2%
based exercise program	30 mins per session	Control: 66.7±5.4/36	07.270
F0	F. C.		
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Adherence rates less than 70% have been highlighted. Adherence rates do not include the control group

Chapter Three: Development of the exercise questionnaire

# Development and validation of a new tool to measure the facilitators, barriers and preferences to exercise in people with osteoporosis

#### **3.0 ABSTRACT**

**Background:** Despite the widely known benefits of exercise and physical activity, adherence rates to these activities are poor. Understanding exercise facilitators, barriers, and preferences may provide an opportunity to personalize exercise prescription and improve adherence. The purpose of this study was to develop the Personalized Exercise Questionnaire (PEQ) to identify the facilitators, barriers, and preferences to exercise in people with osteoporosis.

**Methods:** This study comprises two phases, instrument design and judgmental evidence. A panel of experts was used to validate the instrument through quantitative (content validity) and qualitative (cognitive interviewing) methods. Content Validity Index (CVI) is the mostly commonly used method to calculate content validity quantitatively. There are two kinds of CVI: Item-CVI (I-CVI) and Scale-level CVI (S-CVI).

**Results:** Preliminary versions of this tool showed high content validity of individual items (I-CVI range: 0.50 to 1.00) and moderate to high overall content validity of the PEQ (S-CVI/UA = 0.63; S-CVI/Ave = 0.91). Through qualitative methods, items were improved until saturation was achieved. The tool consists of 6 domains and 38 questions. The 6 domains are: 1) support network; 2) access; 3) goals; 4) preferences; 5) feedback and tracking; and 6) barriers. There are 35 categorical questions and 3 open-ended items.

**Conclusions:** Using an iterative approach, the development and evaluation of the PEQ demonstrated high item-content validity for assessing the facilitators, barriers, and preferences to exercise in people with osteoporosis. Upon further validation it is expected that this measure might be used to develop more client-centered exercise programs, and potentially improve adherence.

#### **3.1 BACKGROUND**

Osteoporosis is characterized by low bone mass and deterioration of bone tissue (1,2). The burden of this disease on individuals and the healthcare system is typically a result of fragility fractures that may result in immobility and hospitalization (3). In 2010, it was estimated that 30% to 50% of women and 15% to 30% of men will suffer an osteoporotic facture in their lifetime (4). Osteoporotic fractures are more common than heart attack, stroke and breast cancer combined and hip fractures caused by this disease utilize more hospital bed days than diabetes, stroke, or heart attack (5). As of 2010, the yearly cost to the Canadian healthcare system for treating an osteoporotic fracture was over 2.3 billion Canadian dollars (5). Thus, fracture prevention strategies are key to reducing this burden. Exercise and physical activity is essential to preserve bone and physical function in patients with osteoporosis. A growing body of literature

focuses on factors that affect exercise adherence including the facilitators and barriers to an exercise program.

Exercise as a means to prevent bone mineral density (BMD) loss has been explored extensively in the literature over the past two decades (2,4,6). Exercise and physical activity are increasingly being recognized as a means to reduce the risk of osteoporotic fractures (2,7) by increasing muscle mass and maintaining or increasing BMD (7–9). Although the terms "exercise" and "physical activity" have distinct definitions, they are often used interchangeably in the literature. Physical activity is defined as "any bodily movement produced by skeletal muscles that result in energy expenditure" while exercise is "any form of physical activity that is planned, structured, repetitive and purposive" and used to maintain or improve physical endurance (10). Since any form of activity is seen as beneficial to this population, this paper will not distinguish between them.

A systematic review in 2013 indicated high variability in adherence to physical activity guidelines, with 2.4% to 83% of older adults meeting the recommendations (11). This variation may indicate that a substantial proportion of people experience major barriers to exercise. In order to further outline the facilitators and barriers to exercise pertinent to patients with osteoporosis, we developed the Personalized Exercise Questionnaire (PEQ), to assess outcomes that were considered important by a panel of patients with low bone mass, physicians, therapists, and researchers. A comparable instrument that measures exercise beliefs exists; however this alone would not be sufficient to identify participant's needs. The Exercise Benefits/Barriers Scale (EBBS) developed in 1987, has 43 questions and uses a 4-point Likert scale: strongly agree, agree, disagree, strongly disagree (12) and has a greater focus on attitudes and beliefs about exercise since the majority of items examine levels of knowledge about specific health benefits of physical activity. A study published in the British Geriatric Society Journal randomly selected 409 older adults determined that almost all participants (95%) believed physical activity was beneficial but barriers such as lack of interest, lack of transportation, pain, disliking going out alone, etc. were deterrents toward exercise adherence (13). These barriers not covered in the EBBS may be more important determinants of exercise adherence. The EBBS also has minimal focus on the specific type of exercises that would be preferred and thus may not directly inform proper exercise prescription. Therefore, the PEQ was designed to address a different conceptual domain than the EEBS. The purpose of the PEQ is to collect

25

information about self-reported facilitators, barriers, and preferences to exercise with the goal of supporting a better understanding of exercise adherence and patient centre exercise prescription for people with osteoporosis.

### **3.2 METHODS**

The PEQ followed the two-step method described by Stein et al. (2007) and Armstrong et al. (2005) (14,15), one involving instrument design and the other obtaining judgmental evidence. Instrument design was performed in a three-step procedure: A) content and domain specification; B) item generation; and C) instrument construction (16). The second step, judgmental evidence (content validity) was conducted with a panel of experts (16).

#### 3.2.1 Step One: Instrument Design

### 3.2.1.1 Content and Domain Specification & Item Generation

Items were generated from the literature retrieved from a PubMed and a CINHAL search to identify publications that evaluated exercise and/or physical activity in the osteoporosis population. Items were generated from a systematic review that evaluated the facilitators and barriers to exercise in patients with osteopenia or osteoporosis and a Belgian focus group study in older adults with osteoporosis that identified motivators and barriers to exercise (17,18). Due to limited research regarding specific motivators and barriers in the osteoporosis population, further items were attained from other populations: A) one from a Canadian focus group study that considered the facilitators and barriers to exercise in women aged 55-70 years (19), B) another from a study that evaluated exercise adherence in middle-aged adults (20), C) the third, from literature that evaluated the facilitators and barriers to exercise in people with hip or knee osteoarthritis (OA) (22). Women and older adults were chosen as similar populations to the osteoporosis group since this disease is more prevalent among women and is often diagnosed in older adults (5). After extracting items and identifying duplicates, 37 unique questions were identified from the literature to construct a preliminary version of the PEQ.

Domains were selected using the Alternative Theory of Planned Behaviour, a combination of the Theory of Planned Behaviour and the Social Cognitive Theory (23). This Alternative Theory analyzes four

concepts: "perceived behavioural control," "attitude toward exercising," "environment," and "normative beliefs" (23). The 37 items were then categorized under one of the four theory concepts. Theory was originally used to create four domains for this tool; however, throughout the iterative development process, the titles were changed to reflect more patient friendly terminologies. For example "*normative beliefs*" was changed to "*support network*" and "*environment*" to "*access*". Additional sections were added based on items found in the literature and some concepts from the Alternative Theory were combined to create new domains. Five domains were identified in the preliminary version: 1) my support network; 2) my access to exercise; 3) exercise goals; 4) my exercise preferences; and 5) my exercise barriers. For simplicity purposes, the following titles will be used when referring to a specific domain: 1) support network; 2) access; 3) goals; 4) preferences; and 5) barriers.

### 3.2.1.2 Instrument Construction

Consistent with the recommendations from Stone, the preliminary version of this tool was circulated to an advisory committee for feedback (24). A three-member committee was asked to evaluate the overall format, domains, and items of the questionnaire. The committee was comprised of a musculoskeletal researcher with a physiotherapy background, an investigator specialized in osteoporosis and exercise research, and a rheumatologist with a specialty in osteoporosis research. The questionnaire was revised through iterative feedback and submitted to a Delphi expert panel comprising of an osteoporosis researcher with a clinical degree in physiotherapy, two doctorate researchers specialized in osteoporosis research, and a kinesiologist. The Delphi technique, developed by the Rand Corporation, was used to seek convergence on this topic because it allows experts to work independently (25). Each domain and item was reviewed for structure and clarity, redundant inquiries eliminated, and ambiguous wording modified.

## **3.2.2 Step Two: Judgmental Evidence (content validity)**

New surveys must be rigorously tested to ensure a tool is valid (26,27). Validity is defined as the extent to which any instrument measures what it is intended to (28). For this reason, the development of the PEQ went through multiple iterations to ensure the survey was clearly worded, well defined, and covered

topics important to patients with osteoporosis. Content validity measures how well items correspond or reflect a specific domain and are measured using quantitative techniques (27,28). Cognitive interview methods can explore how patients with osteoporosis might interpret the meaning of survey items (26). Cognitive interviews were used to determine the following: 1) if participants understood the item; 2) if they understood the item the way the researcher intended, and 3) how participants calibrated the item and its response options. Lastly, focus groups were used to determine how respondents answer survey questions, identify potential problems that lead to response error, and comment on the overall format of the tool.

#### 3.2.2.1 Content Validity

There are multiple methods for testing content validity. This study used one method that involved empirical techniques to calculate the index of content validity (CVI) and the content validity ratio (CVR) and semi-structure cognitive evaluations (15,16). The empirical techniques reviewed in this tool were:

- 1) CVI: CVI is the most widely reported approach for content validity in instrument development and can be computed using the Item-CVI (I-CVI) and the Scale-level-CVI (S-CVI) (16). I-CVI is computed as the number of experts giving a rating of "very relevant" for each item divided by the total number of experts. Values range from 0 to 1 where I-CVI > 0.79, the item is relevant, between 0.70 and 0.79, the item needs revisions, and if the value is below 0.70 the item is eliminated (16). Similarly, S-CVI is calculated using the number of items in a tool that have achieved a rating of "very relevant" (16). There are two methods to calculating S-CVI, one is the Universal Agreement (UA) among experts (S-CVI/UA), and the second, the Average CVI (S-CVI/Ave), the latter being a less conservative method (16). S-CVI/UA is calculated by adding all items with I-CVI equal to 1 divided by the total number of items (16). A S-CVI/UA ≥ 0.8 and a S-CVI/Ave ≥ 0.9 have excellent content validity (29).
- 2) *CVR*: The second type of empirical analysis was CVR, which measures the essentiality of an item (30). CVR varies between 1 and -1, and a higher score indicates greater agreement among panel members (16). The formula for the CVR is  $CVR = (N_e N/2)/(N/2)$ , where Ne is the number of panelists indicating an item as "essential" and N is the total number of panelists (16).

A cover letter and the PEQ were included with the content validity survey explaining why experts were invited to participate, along with clear and concise instructions on how to rate each item. To evaluate whether items were relevant, clear and essential, experts were given a critical appraisal sheet with the following four inquiries: 1) the relevance of each question in the tool (how important the question is); 2) the clarity of each question (how clear the wording is); 3) the essentiality of each question (how necessary the question is); and 4) recommendations for improvement of each question. The critical appraisal tool that experts used to rate the questionnaire is in Appendix A.3. For the relevancy scale, a 4-point Likert scale was used and responses include: 1 = not relevant, 2 = somewhat relevant, 3 = quite relevant, and 4 = very relevant. Ratings of 1 and 2 are considered content invalid while ratings of 3 and 4 are considered content valid (31). A 3-point Likert scale was used for the clarity and essentiality scale since answers can only be trichotomous. The clarity scale was: 1 = not clear, 2 = item needs some revision; and 3 = very clear, and for essentiality: 1 = not essential; 2 = useful, but not essential; and 3 = essential (15,16). Additional comments and recommendations by the experts were written on the hard copy of the questionnaire that was provided with the cover letter.

The recommended number of experts to review an instrument varies from 2 to 20 individuals (15). At least 5 people are suggested to review the instrument to have sufficient control over chance agreement (16). Content validity was determined using a number of experts (n = 6) that included an athletic therapist and a Ph.D. candidate from the University of Western Ontario, a physiotherapist, a chiropractor, and a family doctor from Toronto, Ontario and an orthopedic surgeon with a research background in osteoporosis from McMaster University. Experts were chosen based on the following guidelines: 1) worked in a medical or rehabilitation setting with patients with osteoporosis; or 2) published at least one article related to the care of patients with osteoporosis.

#### **3.2.2.2 Cognitive Interviews**

Cognitive interviewing is a methodology that examines how respondents comprehend, interpret, and answer survey questions (26). The purpose of cognitive interviewing is to obtain information about the process respondents use to answer survey questions, identify potential problems that may lead to survey response error, and gain a better sense of their perception regarding items (32). The question-and-answer model has been cited as a useful representation of how respondents answer survey questions (26). This

29

model suggests four interdependent elements, "comprehension of the information", "retrieval from memory", "decision processes", and "response selection", that interact together and predict how respondents make judgments about the level of detail needed to answer survey questions (33).

Cognitive testing was undertaken specifically with clinicians and patients to evaluate the cognitive process they followed to answer survey questions and to identify items that were not well understood. Techniques used to evaluate clinician and patient understanding of questions were a combination of both the think-aloud and verbal probing (33). Together, these approaches were used to determine how well survey items were understood and how well different response options were reached. Specific think-aloud questions were: "please tell me what you are thinking as you answer this question" or "what steps are going through your head as you pick an option for this question" (32,33). Verbal probes were scripted or spontaneous and scripted questions included, "what do you think the question is asking you" and "please think aloud and tell me how you would answer this question" (26,32,33).

Cognitive interviews were done at McMaster University with 4 Ph.D. graduate students from the Department of Rehabilitation Science who had clinical backgrounds in occupational therapy, kinesiology, and physiotherapy. Interviews were also conducted with 2 patients from Hamilton, Ontario and 9 patients from London, Ontario. All interviews lasted between 1 to 1.5 hours and were recorded and notes were taken. Analytic memos were created based on digital recordings and notes. Memos were coded into the following categories: 1) no problem with the item; 2) minor misunderstanding with the item; and 3) item unclear. Items marked "minor misunderstanding" were reworded, while those marked "unclear" were eliminated, reworded or integrated with another question.

#### 3.2.2.3 Focus Groups

Focus groups are "informal discussions among selected individuals about a specific topic" (34) and can be used to follow up on issues revealed during cognitive interviews or used as a standalone protocol to generate ideas through group discussion (32). Focus groups are typically more open-ended and less structured than cognitive interviews and can help elicit a greater range of responses. In this paper, focus groups were used to elicit respondents' understanding, opinions, and views within the context of discussion and debate with other (34).

30

Two focus groups were held, one at McMaster University and the other at the University of Western Ontario, with 8 and 12 graduate students enrolled in the department of Rehabilitation Science and Physical Therapy, respectively. The majority of students were enrolled in a Ph.D. program. During the focus group, students were given a paper copy of the questionnaire and instructed to read each item and give their thoughts regarding the relevance, clarity and importance of each question. They were also asked to verbalize their thoughts about each item and whether it was in the correct domain. Although a digital recorder was not used, notes were taken during each focus group session.

#### **3.3. RESULTS**

The PEQ underwent 8 rounds of revisions from various expert groups. Table 3.1 summarizes major amendments in Appendix B.3.

## 3.3.1 Content Validity Results

All content validity (CVI and CVR) calculations were from the fifth version (6 domains, 35 questions) of the PEQ.

#### I-CVI Results (Relevancy of individual items)

The I-CVI calculations for the relevancy of each item are in Table 3.2 (Appendix B.3). Thirty-one items (89%) were marked as relevant and the I-CVIs ranged from 0.50 to 1.00. Twenty-two items had an I-CVI = 1.00, nine a score of 0.83, two a score of 0.67, and two a score of 0.50. The majority of items were considered relevant, with the exception of four questions: one on safety of the facility, one on support, and two about feedback.

## S-CVI Results (Relevancy of the overall questionnaire)

The S-CVI/UA = 0.63 and the S-CVI/Ave = 0.91. The Universal Agreement is calculated by adding all I-CVI's equal to 1.00 (22 items) divided by 35, while the Average takes the sum of all I-CVI (31.81) divided by 35. Overall, the Universal Agreement method demonstrates moderate content validity while the Average approach shows high content validity of the PEQ.

### Kappa

Although CVI is extensively used to estimate content validity, Wynd et al suggested that due to chance agreement this index does not consider the possibility of inflated values, and instead suggested a kappa statistic in addition to CVI be calculated (31). Kappa provides the degree of agreement beyond chance, as is calculated using the following formula: K = (I-CVI - Pc)/(1 - Pc), where  $Pc = [N!/A!(N-A)!] * 0.5^N$  (16). In this formula Pc = the probability of chance agreement; N = number of experts; and A = number of experts that agree the item is relevant. Kappa values above 0.74 are considered excellent, between 0.60 to 0.74 good and 0.40 to 0.59 fair. Kappa calculations are in Table 3.3 (Appendix B.3).

#### CVR Results

The CVR was generated for each item. Items that were marked not essential had a CVR < 0.99 (this value is based on the total number of experts, N = 6, and the numerical values of the Lawshe table) (35). Nonessential items can be eliminated, but in this case were not. Twenty-two items out of 35 were marked not essential. Table 3.4 (Appendix B.3) shows a sample of instrument items and the CVR calculations. Thirteen items had a CVR of 1.00, two a score of 0.67, seven a score of 0.66, four a score of 0.33, five a score of 0.00, three a score of -0.33, and one a score of -0.66. The average CVR value was 0.53.

### Clarity Results (Individual items and overall questionnaire)

Clarity was calculated using 6 raters on a 3-point Likert Scale (1 = not clear, 2 = somewhat clear, 3 = very clear). Average clarity scores for individual items ranged from 2.33 to 3.00 with five items (14%) considered *very clear*. Five items had an average clarity score of 3.00, ten a score of 2.83, twelve a score of 2.67, three a score of 2.5, and five a score of 2.33. The overall clarity score of the fifth version of the PEQ was 2.69.

#### 3.3.2 Questionnaire Refinement Results

#### Version One and Two (Three-member panel)

There were two rounds of evaluations; in the first round, items were reworded for clarity and moved to more suitable domains. Two open-ended questions were added to include more information that may not have been captured through closed survey questions. These questions asked respondents to list up to three factors that would help them to exercise more often and up to three factors that prevented them from exercising more often. In the second round, one panel member suggested including several additional items regarding patient progression and feedback since patient perspective is important to be considered in an exercise program and enjoyment is both a predictor and an outcome of physical activity participation (36). Members of the panel unanimously voted to include an additional domain regarding participant's feedback and progress, so a sixth domain and 3 additional items were added. These three additional questions asked participants how they would like to receive feedback on their progression, the type of feedback they would like to receive and how often they would like to receive feedback. The third version of this questionnaire comprised 6 domains and 42 questions (40 categorical and 2 open-ended items).

#### Version Three, Four and Five (Delphi Panel and Patients Cognitive Interviews from Hamilton)

The Delphi Panel underwent three rounds of refinement. In the first round, two questions on pain and one item on mobility were eliminated since the committee felt the items were adequately measured by other questions. One question regarding the type of exercise facility was moved from section two (access to an exercise facility) and combined with a question in section four (exercise preferences). In the second round, 2 out of the 39 items were removed because members felt respondents would not be able to answer questions about their DXA and T-scores. One item regarding fractures was removed and turned into a subitem question in section six. In the third round, two additional questions were added to section 5 about feedback and tracking. The panel thought it would be important to ask participants how they would like to track their exercise progress and if they would like to give feedback about the exercise program.

Patients diagnosed with osteopenia or osteoporosis also reviewed the fifth version of the questionnaire. Two patients from Hamilton, Ontario were recruited from the St. Joseph's HealthCare's

33

Charlton Campus. One female with osteoporosis and one male with osteopenia suggested two additional questions for sections four and six, one on exercise times and the other on weather as a facilitator or barrier to exercise. The questionnaire was then updated to the sixth version (6 domains with 39 questions).

## Version Six (Graduate Student Focus Group + Clinicians enrolled in the Ph.D Stream)

Two focus groups were held, one at McMaster University (n = 8) and the other at the University of Western Ontario (n = 12). Students at McMaster University were predominantly female (75%) and at the University of Western Ontario mostly male (66%). Both focus groups gave feedback on wording and terms consistency suggesting patients might confuse the terms "*exercise*" and "*workout*" or "*survey*" and "*questionnaire*". It was recommended to use one term but not both. It was also suggested to use patient friendly terminology. Students suggested terms such as "*exercise movement*", "*fracturing a bone*", "*access to an exercise facility*" and "*limited range of movement*" be reworded. Students agreed that the font and spacing of sentences were adequate and the use of underlining was well done. They also believed all questions were appropriate and well worded with minor changes in terminology.

One-on-one interviews with clinicians in the Ph.D. stream (n = 4) were all females. All graduate students reviewed the sixth version of the questionnaire (6 domains with 37 questions) and were inquired to open an envelope and briefly look at each page of the survey. Subsequently, they were inquired to describe their initial impression and comment on the layout, response options, and overall flow of the questionnaire. Next, respondents were asked to go over each survey item and comment on its clarity, relevance, and importance. All participants stated the font, spacing, and length was acceptable however, specific item revisions were required. One proposed that the phrase, "if applicable, check any AIDS or DEVICES that you usual use..." should be changed to "if applicable, please check any mobility AIDS or DEVICES that you usual use." Others suggested examples or additional words within parenthesis be added after items to clarify or define answer choices. For example in question 7, "*I have a safe place to exercise*", the phrase "*e.g. proper space to exercise, dry and clean floors, good lighting, etc.*" was included in parenthesis after the question. They also suggested including, in parenthesis, after each question the following options: 1) "*check ALL that apply*"; or 2) "*check only one answer*" to clarify how many answers respondents could mark. Additional barriers to exercise were also suggested such as "*poor quality of sleep*" and "*not liking*"

*exercise*". Items were added as sub-categorical answers to existing questions. One question regarding selfconfidence was removed and turned into a sub-item question and another in section two about exercise safety was removed since most clinicians felt it was already measured by a previous question.

## Version Seven and Eight (Patient Cognitive Interviews)

Nine patients, five females and four males, from London, Ontario, were recruited from the Hand and Upper Limb Clinic (HULC) at St. Joseph's Health Care Centre and all had a history of fractures. There were two rounds of judgment. Five patients assessed the seventh version of the questionnaire. Participants stated the instructions were simple and easy to understand and that items were clear but answer choices needed additional words or phrases. A few participants felt some questions were not applicable to them, and the inclusion of a "Not Applicable" category was important. Patients also found it difficult to complete section three, exercise goals. The questionnaire initially asked patients to rank the following goals in order of importance from 1 to 7, where 1 was the most important and 7 the least important. Answers were broad, with some patients ranking their goals from 1 to 7 and others ranking all goals with the same number. One participant thought he could only use the numbers 1 and 7 to rank. Section three was restructured to a 4point Likert Scale (*not important, somewhat important, very important, not* applicable) and an open ended question that asked participants what their most important goal was, was added. The eighth version was then submitted for a second round of judgment. Four patients reviewed the eighth version of the questionnaire; there were no significant changes, with patients commenting on changes that were not applicable to the majority of people.

After compiling all advice from experts, the final version of the PEQ had 6 domains with 38 items, 35 close ended and 3 open-ended questions (see Appendix C.3).

#### Readability Grade Levels

Readability levels were calculated for the eighth version of this questionnaire. The Flesch-Kincaid Grade Level and SMOG Index were calculated electronically (http://www.readabilityformulas.com/free-readability-formula-tests.php) and rate how easily sentences in the tool can be read and understood. The Flesch-Kincaid Grade level was 5.8 indicating it is easy to read and can be understood by an average 11-

year old student. The SMOG Index was 6.9 demonstrating a seventh grade reading level.

## **3.4 DISCUSSION**

This study developed and provided content validation of the Personalized Exercise Questionnaire (PEQ) that assesses multiple domains relating to the facilitators, barriers, and patient preferences in relation to exercise. Although the questionnaire was developed with the osteoporosis population as a primary target, the majority of items are not specifically related to osteoporosis suggesting that the questionnaire may be useful in a variety of other populations upon further validation.

The PEQ provides a unique self-report tool to assist with assessment of factors that may support or hinder the adoption and maintenance of regular exercise. Since it is well-known that adherence to exercise, physical activity, or home-based therapeutic exercise is problematic, it is the intention that the PEQ might support assessment of facilitators, barriers, and personal preferences in groups of people or be used to develop more personalized exercise recommendations for individuals to ultimately increase exercise participation. An article by Crombie et al found the levels of knowledge about specific health benefits of exercise were high, yet the majority of older adults did not participate in any physical activity. The authors suggest national campaigns to encourage exercise and physical activity (13), however, persuading individuals with barriers to exercise may be difficult. Thus strategies to increase activity levels must include identifying the facilitators, barriers and patient preferences to an exercise program and compiling these factors using the PEQ to encourage participation.

The most common method for measuring content validity is calculating the Item-level CVI (I-CVI), however, an alternative, unacknowledged method to measure content validity is Scale-level CVI (S-CVI), which can be calculated using S-CVI/UA or S-CVI/Ave. The two approaches can lead to different values, making it difficult to draw the proper conclusion about content validity (37). I-CVI measures the content validity of individual items while the S-CVI calculates the content validity of the overall scale. Most papers report the I-CVI or the S-CVI but not both. This paper considered both the I-CVI and the S-CVI since the S-CVI is an average score that can be skewed by outliers. The number of experts (n=6) was considered adequate for content validation as the number of raters ranges from a minimum of 3 to a maximum of 10 (16,30). An I-CVI of 0.78 or higher is considered excellent. The I-CVIs of all items in the

PEQ ranged from 0.50 to 1.00 with only four items having an I-CVI less than 0.78. This supports the conclusion that individual items were important and relevant to measuring the facilitators, barrier and patient preferences to an exercise program. The minimum acceptable S-CVI is considered to be any value between 0.80 to 0.90 (30,37). Two values were calculated: S-CVI/UA and S-CVI/Ave. The Universal Agreement approach suggested the overall content validity of the PEQ was moderate (S-CVI/UA = 0.63), while the Average method suggested high content validity (S-CVI/Ave = 0.91). Although the Universal Agreement method only considers items that have an I-CVI of 1.00 and may be considered more comprehensive than the Average approach, this method may be underestimating content validity of the number of experts increases. The alternative and less constricted method is the S-CVI/Ave approach that may be overestimating content validity since the numerator in the Average technique will always be greater than the numerator of the Universal Agreement approach if I-CVI values are not all equal to 1.00. For this reason both the S-CVI/UA and the S-CVI/Ave were calculated and the true overall content validity of the PEQ may be somewhere in-between.

A less common way to calculate content validity is to use the CVR approach. This method determines how many raters mark an item as essential. Thirty-one items had a positive CVR value indicating at least half the raters considered the items to be essential, with an overall suboptimal content validity score, CVR = 0.53. It is possible that raters did not understand the item since only 14% of questions were considered *very clear*. Items were marked relevant indicating they were directly related to the topic but due to poor clarity raters may not have clearly understood what the item was measuring resulting in a low CVR score. The next step in instrument develop was to improve the item clarity using qualitative evaluations. Quantitative methods strongly supported individual items in the PEQ, and the use of cognitive interviews and focus groups were used to further refine the clarity of the language.

The complexity of doing numerous rounds of cognitive interviews and focus groups was to decide what information was relevant and when information was no longer considered important in tool development. The goal of cognitive assessments and subsequent revisions was to reach a point where there was sufficient evidence of no problems with item comprehension; at this point saturation has been

achieved. Overall, the PEQ benefited from multiple consultations and iterative revision, which contributed to substantial changes in the types of items, concepts, wording, response options, and the overall structure of the questionnaire. Lack of clarity, misinterpretation, and ambiguity of items were the primary reasons for instrument modifications. It became clear that multiple iterations were essential since repeat consultations with people who had previously seen early versions had additional recommendations. There is no clear indication of the optimal number of revisions required to be certain that a measure is well developed (38). However, the concept of saturation applies in iterative feedback when no recommendations being made are considered useful or that multiple respondents can agree upon. The PEQ underwent three additional rounds of revisions with a heterogeneous interview sample until feedback was not applicable to the majority. Content validity calculations (CVI and CVR) were not necessary to be measured again in the final version of the PEQ since content validity of individual items was excellent. Furthermore, rigorous qualitative research provided evidence of high content validity of the overall PEQ by reaching saturation through interviews with multiple experts.

Understanding factors affecting exercise adherence measured across multiple domains may help develop targeted interventions that may increase the quality and delivery of physical activity programs. This tool has potential applications in both the research setting and in clinical practice. Investigators can use this tool to survey their population of interest and use this information to inform decision-making about the type, frequency, and location of the exercise for the majority. The goal of designing an exercise program in research is to encourage individuals to continue the program long after the intervention has finished. Identifying an exercise program that increases muscle and bone mass, catered towards patient needs, will be one way of increasing exercise adherence. This tool can also help clinicians identify and design better exercise prescriptions for individual clients. It is important for healthcare providers to identify their patients' facilitators, barriers, and exercise goals before giving specific recommendations since understanding these factors may result in better and more effective exercise prescriptions.

## **3.5 LIMITATIONS**

With any preliminary questionnaire there were some limitations to its design. The limitations of this study include: (1) potential lack of generalizability; (2) risk of using a self-reported measure; and (3)

length of the questionnaire. Although the PEQ was designed for people with osteoporosis it may be applicable in elderly populations, but its generalizability to other clinical populations is unknown and must be tested. Secondly, with all self-reported measures there is a risk of recall bias or inflated answers to reflect lower impediments to exercise. The questionnaire also takes about 20 to 30 minutes to complete.

# **3.6 CONCLUSION**

The PEQ is the first instrument that assesses the facilitators, barriers and preferences to exercise in people with osteoporosis. The design of this questionnaire used a mixed-method approach to select items necessary to understand the facilitators, barriers, and preferences to exercise. The PEQ showed high content validity of individual items (I-CVI range: 0.50 to 1.00) and moderate to high content validity of the overall questionnaire (S-CVI/UA = 0.63; S-CVI/Ave = 0.91). Through qualitative methods, clarity of items was refined. The next chapter of this dissertation will determine the dimensionality, construct validity and test-retest reliability of the PEQ. Once these concepts are established, future physical activity or exercise interventions could benefit from using this tool to leveraging the facilitators and limiting the barriers to exercise to increase adherence to an exercise program.

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# 3.8 APPENDIX A.3

## Critical appraisal of the checklist of facilitators and barriers to exercise

Title of Study: Reliability and validity study of the Facilitators and Barriers to Exercise Questionnaire

**Student Investigator:** Isabel B Rodrigues, B.Sc. (Hons), M.Sc. (candidate) Department of Rehabilitation Sciences McMaster University Hamilton, ON, Canada (905)-865-7426 E-mail: rodrigib@mcmaster.ca

## WHAT IS THE PURPOSE OF THIS STUDY?

You are being invited to participate in a research study conducted by Isabel B Rodrigues to validate a new survey that will measure the facilitators and barriers to exercise in people with osteopenia and/or osteoporosis.

## INSTRUCTIONS FOR VALIDATING THE QUESTIONNAIRE:

This tool has 35 questions that fall into the following six domains:

- 1. Community Support Network
- 2. Access to Community Facilities
- 3. Exercise Goals
- 4. Facilitators to Exercise
- 5. Feedback and Tracking
- 6. Barriers to Exercise

Kindly review this tool and provide your feedback on the following:

- 1. The relevance of each question in the tool (how important is the question)
- 2. The clarity of each question (how clear is the wording)
- 3. The essentiality of each question (how necessary is the question)
- 4. Recommendations for improvement of each question

If you have any comments or correction regarding the Facilitators and Barriers to Exercise Questionnaire, please make them on the copy provided.

Please complete the following questions:

1. Do you have a professional license?

Yes
No

If YES, please specify: \_\_\_\_\_

2. For how long have you been practicing?\_\_\_\_\_\_

3. Where is your practice located (*city only*)?\_\_\_\_\_\_

**<u>Relevant Scale:</u>** 1= Not relevant; 2 = Somewhat relevant; 3 = Quite relevant; 4 = Very relevant

**<u>Clarity Scale:</u>** 1= Not clear; 2 = Item needs some revision; 3 = Very clear

<b>Essential Scale:</b> 1 = Not essential; 2 = Useful but not essential; 3 =	= Essential
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Section	One									
	Hc	w relevan	t is this it	em?	Is t	nis item c	lear?	How es	How essential is this item?	
Q1.	01	02	03	04	01	02	03	01	02	03
Q2.	01	02	03	04	01	02	03	01	02	03
Q3.	01	02	03	04	01	02	03	01	02	03
Section	Two				1			1		
			t is this it	em?		nis item c	lear?	How es	ssential is t	his item?
Q 4.	01	02	03	04	01	02	03	01	02	03
Q 5.	01	02	03	04	01	02	03	01	02	03
Q 6.	01	02	03	04	01	02	03	01	02	03
Q 7.	01	02	03	04	01	02	03	01	02	03
Q 8.	01	02	03	04	01	02	03	01	02	03
Section			tic this it	- m 2	Ic th	ais itom s	1005		contial is t	his itom?
	пс	w retevan	t is this it	em?	15 נו	nis item c	lear?	Howles	ssential is t	nis item?
Q 9.	01	02	03	04	01	02	03	01	02	03
Q10.	01	02	03	04	01	02	03	01	02	03
Q11.	01	02	03	04	01	02	03	01	02	03
Q12.	01	02	03	04	01	02	03	01	02	03
Q13.	01	02	03	04	01	02	03	01	02	03
Q14.	01	02	03	04	01	02	03	01	02	03
Q15.	01	02	03	04	01	02	03	01	02	03
Q16.	01	02	03	04	01	02	03	01	02	03
Section				-	-					
	н	ow releva	nt is this i	tem?	Is this item clear?		How essential is this item?		this item?	
Q17.	01	02	03	04	01	02	03	01	02	03
Q18.	01	02	03	04	01	02	03	01	02	03
Q19.	01	02	03	04	01	02	03	01	02	03
Q20.	01	02	03	04	01	02	03	01	02	03
Q21.	01	02	03	04	01	02	03	01	02	03
Section	r				-					
000			nt is this i	[		this item			essential is	
Q22	01	02	03	04	01	02	03	01	02	03
Q23	01	02	03	04	01	02	03	01	02	03
Q24	01	02	03	04	01	02	03	01	02	03
Q25	01	02	03	04	01	02	03	01	02	03
Q26	01	02	03	04	01	02	03	01	02	03
Section		w relevan	t is this it	am?	Ic ti	nis item c	loar?		sential is t	his itom?
Q27		1	1	1		1	1			
Q27 Q28	01	02	03	04	01	02	03	01	02	03
Q28 Q29	01	02	03	04	01	02	03	01	02	03
Q29 Q30	01	02	03	04	01	02	03	01	02	03
Q30 Q31	01	02	03	04	01	02	03	01	02	03
Q32	01	02	03	04	01	02	03	01	02	03
Q32 Q33	01	02	03	04	01	02	03	01	02	03
Q35 Q34	01	02	03	04	01	02	03	01	02	03
Q35	01	02	03	04	01	02	03	01	02	03
<b>6</b> 22	01	02	03	04	01	02	03	01	02	03

# **3.9 APPENDIX B.3**

# Table 3.1: Iterative Summary of changes to the PEQ

Version Number	Reviewers	Total Number of Items in the beginning/ Total Number of Items in the end	Substantial (important) changes
Version 1	Three-member panel	37 / 39	<ul> <li>Items rearranged to the most appropriate domains</li> <li>Addition of 2 open ended questions (patients to list up to 3 facilitators and barriers to exercise)</li> </ul>
Version 2	Three-member panel	39 / 42	<ul> <li>Addition of 1 domain (Section Five: "Feedback and Tracking")</li> <li>Addition of 3 questions on "feedback and tracking"</li> </ul>
Version 3	Delphi panel of experts	42 /38	<ul> <li>Removal of 4 questions (2 on pain, 1 on mobility, and 1 about the exercise facility)</li> </ul>
Version 4	Delphi panel of experts	38 /35	<ul> <li>Removal of 2 questions (1 on a patient's last DEXA scan and 1 on a patient's T-score)</li> <li>Removal of 1 barrier question on fractures (turned into a sub-item question)</li> </ul>
Version 5	Delphi panel of experts Patients from Hamilton, Ontario	35 / 39	<ul> <li>Addition of 2 questions in the "Feedback and Tracking"</li> <li>Addition of 2 questions (1 on weather, 1 on exercise times)</li> </ul>
Version 6	Clinicians enrolled in the Ph.D. Stream Two student focus groups	39 / 37	<ul> <li>Removal of 1 question on confidence (turned into a sub-item question)</li> <li>Removal of 1 question in Section 2 about exercise safety (question already measured by another item)</li> </ul>
Version 7	Patients from London, Ontario	37/38	<ul> <li>Revised response of Section 3 on "Exercise Goals"</li> <li>Addition of 1 open ended questions regarding "the most important goal" in Section 3</li> <li>Change from a 3 point to a 4-point Likert scale for sections 1, 2 and 3 to add a <i>Not Applicable</i> box</li> </ul>
Version 8	Patients from London, Ontario	38/38	<ul> <li>No significant changes made; changes applied to a limited number of individuals</li> </ul>

# Table 3.2: Calculation of the I-CVI for relevancy and clarity for each item (version 5)

Item	I-CVI (Relevancy)	Interpretation	I-CVI (Clarity)	Interpretation
Q1	1.00	Relevant	0.33	Not Clear
Q2	1.00	Relevant	0.83	Clear
Q3	1.00	Relevant	0.83	Clear

	1			- F
Q4	1.00	Relevant	0.83	Clear
Q5	1.00	Relevant	0.67	Not Clear
Q6	0.50	Eliminated	0.67	Not Clear
Q7	0.50	Eliminated	0.33	Not Clear
Q8	1.00	Relevant	0.83	Clear
Q9	1.00	Relevant	1.00	Clear
Q10	1.00	Relevant	0.83	Clear
Q11	0.83	Relevant	0.67	Not Clear
Q12	1.00	Relevant	1.00	Clear
Q13	1.00	Relevant	1.00	Clear
Q14	1.00	Relevant	1.00	Clear
Q15	1.00	Relevant	1.00	Clear
Q16	0.83	Relevant	0.67	Not Clear
Q17	1.00	Relevant	0.67	Not Clear
Q18	1.00	Relevant	0.83	Clear
Q19	0.83	Relevant	0.83	Clear
Q20	0.83	Relevant	0.67	Not Clear
Q21	0.83	Relevant	0.67	Not Clear
Q22	1.00	Relevant	0.83	Clear
Q23	0.67	Eliminated	0.67	Not Clear
Q24	0.83	Relevant	0.83	Clear
Q25	0.67	Eliminated	0.83	Clear
Q26	1.00	Relevant	0.67	Not Clear
Q27	1.00	Relevant	0.67	Not Clear
Q28	1.00	Relevant	0.83	Clear
Q29	0.83	Relevant	0.50	Not Clear
Q30	1.00	Relevant	0.67	Not Clear
Q31	1.00	Relevant	0.50	Not Clear
Q32	1.00	Relevant	0.83	Clear

Q33	0.83	Relevant	0.67	Not Clear
Q34	0.83	Relevant	0.67	Not Clear
Q35	1.00	Relevant	0.67	Not Clear

NOTE: Number of items considered relevant and clear by all experts, N = 6.

# Table 3.3: Kappa Score for relevancy of each item (version 5)

Item	Pc (Probability of chance agreement)	Kappa statistic	Interpretation
Q1	0.016	1.00	Excellent
Q2	0.016	1.00	Excellent
Q3	0.016	1.00	Excellent
Q4	0.016	1.00	Excellent
Q5	0.016	1.00	Excellent
Q6	0.313	0.27	Eliminated
Q7	0.313	0.27	Eliminated
Q8	0.016	1.00	Excellent
Q9	0.016	1.00	Excellent
Q10	0.016	1.00	Excellent
Q11	0.094	0.81	Excellent
Q12	0.016	1.00	Excellent
Q13	0.016	1.00	Excellent
Q14	0.016	1.00	Excellent
Q15	0.016	1.00	Excellent
Q16	0.094	0.81	Excellent
Q17	0.016	1.00	Excellent
Q18	0.016	1.00	Excellent
Q19	0.094	0.81	Excellent
Q20	0.094	0.81	Excellent
Q21	0.094	0.81	Excellent
Q22	0.016	1.00	Excellent

Q23	0.234	0.57	Eliminated
Q24	0.094	0.81	Excellent
Q25	0.234	0.57	Eliminated
Q26	0.016	1.00	Excellent
Q27	0.016	1.00	Excellent
Q28	0.016	1.00	Excellent
Q29	0.094	0.81	Excellent
Q30	0.016	1.00	Excellent
Q31	0.016	1.00	Excellent
Q32	0.016	1.00	Excellent
Q33	0.094	0.81	Excellent
Q34	0.094	0.81	Excellent
Q35	0.016	1.00	Excellent

# Table 3.4: Calculating of CVR for the PEQ (version 5)

Item	Scale name/Main content	CVR	Interpretation
Q1	A supervised exercise program	1.00	Remained
Q2	A healthcare provider with a positive attitude toward exercise	0.00	Eliminated
Q3	Having friends/family with a positive attitude toward exercise	0.67	Eliminated
Q4	An exercise facility in my area	1.00	Remained
Q5	Transportation to an exercise facility	0.67	Eliminated
Q6	A safe place to exercise		Eliminated
Q7	An outdoor/indoor area where I can exercise in a supportive and pleasant environment		Eliminated
Q8	An exercise facility that is free of cost or reasonably priced	1.00	Remained
Q9	Have less pain	1.00	Remained
Q10	Feel less tired	1.00	Remained
Q11	Be able to walk longer	0.33	Eliminated
Q12	Be more flexible	1.00	Remained

Q13	Have better balance	1.00	Remained
Q14	Increase muscle strength	1.00	Remained
Q15	Experience less falls	1.00	Remained
Q16	Top three exercise goals	- 0.33	Eliminated
Q17	Exercise pain	0.66	Eliminated
Q18	Exercise location	0.66	Eliminated
Q19	Exercise group size	0.00	Eliminated
Q20	Exercise schedule	0.33	Eliminated
Q21	Type of exercise	0.00	Eliminated
Q22	Receive feedback about exercise progress	0.66	Eliminated
Q23	Type of feedback	0.00	Eliminated
Q24	How often would you like to receive feedback about your exercise progress	0.33	Eliminated
Q25	Giving feedback on an exercise program	- 0.66	Eliminated
Q26	Tracking an exercise program	0.66	Eliminated
Q27	Do you have things that prevent exercise	1.00	Remained
Q28	Exercise fears	1.00	Remained
Q29	Exercise difficulties	0.66	Eliminated
Q30	Do you think you have barriers to exercise	1.00	Remained
Q31	Other medical conditions	1.00	Remained
Q32	Additional priorities	0.00	Eliminated
Q33	Likelihood of exercising if barriers were limited	0.66	Eliminated
Q34	Self-conscious about exercising	0.33	Eliminated
Q35	Limited mobility due to fractures	0.66	Eliminated

NOTE: Number of experts evaluated the item essential. CVR = (Ne - N/2)/(N/2) with 6 person at the expert panel (N = 6), items with the CVR bigger than 0.99 remained in the questionnaire and the rest eliminated.

## Major revisions (in detail)

The final version of section one, support network, consisted of 3 questions regarding normative beliefs and measured how patients may perceive the attitude of salient individuals and groups toward

exercise. Content validity results suggested all three questions were relevant, but questions 2 and 3 (the attitudes of healthcare providers, friends and families toward exercise) were not essential and should be eliminated. Although expert opinions are important to consider there is strong evidence in the literature to support these questions. A systematic review identifying the facilitators and barriers to exercise and a qualitative focus group study on exercise adherence in older adults found physical therapists with a positive attitude toward exercise and a program under the supervision of a physiotherapist of a healthcare professional was a motivator for some patients (19,23). Furthermore, a systematic review of barriers and facilitators to exercise found support from family members and friends, particularly from a spouse, was a positive motivator that encouraged participants to be physically active (41). This study has been corroborated by two literature reviews that identified barriers and facilitators in people with knee OA and older adults (24,42). Questions 2 and 3 were not removed, but rephrased to better capture what the questions were measuring.

Section two had 6 questions in the eighth version and measured how easily participants access an exercise facility. Questions 4 and 8 (exercise facility distance from home/work was and the cost) were considered relevant and essential while items 5 to 7 (transportation, safety, and the type of environment) were marked not essential. In addition, questions 6 and 7 were also marked irrelevant. Although items regarding safety and the type of environment were considered for elimination, qualitative research strongly supports them and they were retained in the tool. Humpel and Owen found a consistent association between environmental factors and exercise behaviours (43) and measuring this concept will be important in understanding the facilitators and barriers to exercise. A study that identified the facilitators and barriers to exercise in people with osteoarthritis reported 52% (12 of the 23) identified factors related to environmental issues (24). Furthermore, a Canadian focus group revealed the following important barriers to exercise: "There is no bus service on the weekend and during the week it is only offered in the early morning or from 4 p.m. to 6 p.m. with limited stops"; "Safe dressing rooms are important. Floors are wet and hooks are too high which means having to stand on benches, this is very dangerous"; "We need instructors that are older, that will not push you like the younger ones, that understand your issues" (21). Qualitative literature strongly supports keeping these questions, however, further research regarding the verification of these environmental components should be considered. It is possible that experts did not understand the

questions, since items 5 to 7 were marked unclear. During cognitive interviews with patients and clinicians, these questions were reworded to improve their readability.

The third domain measures exercise goals and patient preferences using 8 questions. In 2003, the World Health Organization (WHO) recommended one method to improve adherence rates was through patient-tailored interventions that take into account patient preferences (44). When patients are not engaged in clinical decision making, they may feel less empowered resulting in lower adherence rates (42). Literature from the Canadian focus group study identified activities of daily living such has being able to lift groceries, climb stairs, play with grandchildren, gardening, walking, and completing housework as important goals. Additional items were also identified from the systematic review that identified the facilitators and barriers to exercise in people with osteopenia and osteoporosis including having less pain and being more flexible (19). Goal setting is an important context to explore and has been found to be a short and a long term barrier to exercise (24). This questionnaire can be used to measure both short and long term goals. Patient reported goals were consolidated into 7 generic objectives. Items like "feeling less tired" encompass many goals such as being able to climb stairs or playing with grandchildren. An openended question that asks participants their most important exercise goal was used for dual purpose: (1) to capture other intentions that may have been missed from the previous 7 goal questions; and (2) to force participants to choose one important goal. Cognitive interviews with patients revealed this was the hardest section for most because it required complex, non-algorithmic thinking. Ranking items requires considerable cognitive effort that may cause anxiety. Questions were arranged so that participants required some degree of effort but not to the point of mindlessly answering questions. All items were marked as relevant and essential except question 11 ("be able to walk longer"). This item was also marked unclear, so it's possible experts did not understand the question. Subsequent versions of the PEQ have improved the clarity of the items in this domain.

Considering a wide range of exercise motives is a novel approach when developing an exercise program (45) and section four identifies possible facilitators to exercise using 7 questions. Experts considered all items relevant but not essential and unclear. After reviewing items with Ph.D. candidates with clinical backgrounds and patients with osteopenia or osteoporosis, questions were found to be biased

and/or unclear. Many items in this section originally asked about how exercise reduced pain and were eliminated. All questions were reformed to better represent items that were less biased and focused more on exercise preferences such as preferred exercise locations, exercise group sizes, schedule and type of exercises.

Section five of the PEQ was only included during the third revision by an expert member who suggested the inclusion of this domain since the use of Physical Activity Monitors (PAMs) are becoming a fairly inexpensive and available method to track activity (46). The content validity values for this domain suggested all items should be eliminated although the majority of items were found to be relevant. It is possible that experts believe that many older adults track exercise habits using the pencil and paper method or their memory and that this domain was unnecessary. However, there is evidence supporting older adults are becoming more interested in and capable in using technology to track exercise behaviours (46,47). There is strong evidence that tacking ones exercise habits and receiving positive reinforcement improves exercise adherence (48). Although experts believe this domain to be redundant previous evidence has shown tracking increases exercise behaviours and understand how patients would like to track their progress may be important. Pilot testing of this instrument may determine the usefulness of this section.

Barriers to exercise may be considered one of the strongest influencers that prevent people from exercising. Section six may be considered the most important part of the questionnaire and consists of 8 questions identified through qualitative research in the osteoarthritis population and women's focus group study from Canada (21,42). Additional items were identified from a systematic review that looked at facilitators and barriers in the general population (41). Barriers identified included inconvenient class sessions, cost and location, intimidating gym atmosphere, dislike of the music and/or television and lack of confidence when operating gym equipment. All items were considered relevant, however most were marked not essential and unclear. Considering all questions were marked as relevant, it is possible that the clarity of items resulted in them being ranked not essential. Feedback from clinicians and patients helped design clearer and more succinct questions. Barriers may be more important than facilitators since this may affect adherence more than other factors. For example a person with accesses to an exercise facility may be impeded due to financial costs. In some cases barriers may outweigh all factors and investigators should

weight barriers to exercise more strongly than facilitators.

The overall layout of the tool was designed to minimize boredom and combines cognitively difficult questions with easy ones. Stone et al recommends the initial part of a question be neutral but interesting with more sensitive items at the end (26). This questionnaire was designed get progressively more difficult with more challenging questions followed by some easier items to alleviate cognitive load. Section one and two were chosen as the first and second domain since they are relatively easy to complete. The third section is also simple, but requires a little rational since it asks participants to rank their exercise goals. Section four, starts of with an open-ended question that may require some time to complete, but is then followed by easier items. An easier section regarding tracking and feedback during an exercise program follows section four. The last section, barriers to exercise, requires the most cognitive skills and takes the most time. This questionnaire takes about 20 to 30 minutes to complete.

A 4-point Likert scale was used in domains 1, 2 and 3. The reliability of a 5 to 7 point Likert scale is stronger than a 4-point scale, however the 4-point scale was more appropriate since most patients with osteoporosis are 50 plus and smaller scales are simple to use and less cognitively demanding. A 4-point ordinal scale also avoids having neutral or ambivalent midpoint answers. Lastly, unlike other measures that are completed at multiple time points, respondents complete this questionnaire once and it is unnecessary to test the accuracy of answer choices.

There are a couple of questions in this instrument that may seem redundant and have overlapping themes. For example question 6 in domain 2 assesses participants transportation to an exercise facility, similar to question 34 in section 6. These repeat questions act as decoys to determine mismatches in participant answers. Possible conflicting answers may indicate item misinterpretation.

The PEQ was designed to identify possible facilitators and barriers to exercise in patients with osteopenia and osteoporosis. A series of questions have been posed in a clear, comprehensible, and appropriate manner so that respondents can for formulate, articulate and transmit their answers effectively. Although this questionnaire was intended for people with osteoporosis, it may be suited for older adults since many items were identified from literature in mature adults.

Chapter Four: Validation and Reliability of the PEQ

# Determining Known-Group Validity and Test-Retest Reliability of the PEQ (Personalized Exercise Questionnaire)

## 4.0 ABSTRACT

**Objective:** To determine the known-group validity (type of construct validity) and the test-retest reliability of a newly developed tool, the Personalized Exercise Questionnaire (PEQ), that assesses the barriers, facilitators and preferences to exercise in individuals with osteopenia and osteoporosis.

**Methods:** A comparative design was used to assess known-group validity and a test-retest design to examine the reproducibility. Ninety-five participants with osteopenia or osteoporosis were recruited from an outpatient clinic in Hamilton, Ontario. The questionnaire was administered to 95 participants at baseline and a subset of 42 participants completed the survey again 1 week later. The known-group validity of the PEQ was determined using 4 hypotheses that compared two known groups based on employment level, age, socioeconomic status, and physical activity level. The reproducibility of individual responses was analyzed using the Kappa Coefficient.

**Results:** Three out of 4 hypotheses were validated. Test-retest reliability scores ranged from no agreement to almost perfect agreement; 7 items had almost perfect agreement (0.81 - 1.00), 12 substantial agreement (0.68-0.74), 6 moderate agreement (0.56 - 0.60), 2 fair agreement (0.36-0.40), 1 slight agreement (0.23) and 1 no agreement (-0.03).

**Conclusion:** The PEQ was designed to identify potential barriers, facilitators and preferences that might influence exercise adherence. Preliminary support for the usefulness of the PEQ is indicated since the majority of the items had at least substantial test-retest reliability, and known-group validity was moderately supported. The usefulness of the PEQ as a tool to devise patient-centered exercise programs that promote adherence in people with osteopenia and osteoporosis should be evaluated. **Trial Registry:** This study was registered with ClinicalTrials.gov, identifier: NCT03125590

## 4.1 BACKGROUND

Regular physical activity is an important component of maintaining a healthy lifestyle and an essential factor for prevention of osteoporosis. Yet, despite the well-known benefits of regular activity, surveys found more than 60% of adults do not engage in regular exercise and 31% do not participate in any activity (1). A systemic review that reported the facilitators and barriers to exercise in the osteoporosis population found adherence rates between programs varied considerably, ranging from 51.7% to 100% (2). One method that might increase exercise adherence is to understand the factors that affect the motivators, barriers and preferences to physical activity and employ methods to leverage facilitators and preferences and limit barriers to create customized exercise programs (1). Questionnaires are the most frequently used method of data collection in the field of Rehabilitation Sciences and the most feasible option to survey

large populations (3,4). These self-report questionnaires may be one method to collect data regarding factors that affect exercise adherence. Understanding the factors affecting exercise adherence may help develop targeted interventions that increase the quality and delivery of physical activity programs in the research setting and in clinical practice. (4). A growing body of literature has examined levels of physical activity among different populations using self-reported questionnaires and there is an increased interest to integrate patient-reported outcomes into clinical practice (3).

Exercise is widely recommended to reduce the effects of osteoporosis, falls and related fragility fractures and a number of systematic reviews found weight-bearing exercises help maintain or increase bone mineral density (BMD) in the hip and spine of women with osteopenia and osteoporosis (5–8). The effects of exercise are not only concentrated in reducing the consequences of osteoporosis but also play an important role in improving daily activities (9). A recent systematic review found exercise also improves activities of daily living (i.e. dressing, bathing, etc.) in participants with osteoporosis (9).

We previously described the developmental process and content validity of the Personalized Exercise Questionnaire (PEQ), a self-reported survey that assesses the motivators, barriers, and patient preferences to exercise (10). The PEQ was developed from a number of systematic reviews of the literature, expert advice and participant feedback. In that previous paper, the PEQ demonstrated high content validity of individual items (I-CVI range: 0.50 to 1.00) and moderate to high overall content validity (S-CVI/UA = 0.63; S-CVI/Ave = 0.91) among healthcare providers and investigators (10). This article describes the sequential steps in the development and testing of the PEQ using data collected from patients with osteopenia or osteoporosis. The purposes of this study were to describe the:

- 1. Dimensionality of the PEQ using exploratory factor analysis (EFA);
- 2. Cross-sectional construct validity by testing differences between two or more groups with expected differences to establish known-group validity (11);
- 3. Test-retest reliability of individual items of the PEQ by measuring the stability of an item's response over time (11);

## 4.2 METHODS

#### 4.2.1 Ethics

The study was carried out in accordance with the Code of Ethics from the Hamilton Integrated Research Ethics Board (HiREB) and was associated with the research project administered through St. Joseph's Healthcare Hamilton and McMaster University. The Research Ethics Board in Hamilton approved this project on February 24, 2017 (project number: 2682).

#### 4.2.2 Development of the PEQ

The PEQ is intended to evaluate and identify motivators, barriers and preferences to exercise in people with osteoporosis (10). The PEQ followed the two-step method described by Stein et al. (2007) and Armstrong et al. (2005) (12,13), one involving instrument design and the other obtaining judgmental evidence. Instrument design was performed in a three-step procedure: A) content and domain specification; B) item generation; and C) instrument construction. The second step, judgmental evidence (content validity) was conducted with a panel of experts (14). Using an iterative approach, the development and evaluation of the PEQ consists of 6 domains and 38 questions (35 multiple choice and 3 open ended). The 6 domains include: 1) my support network, 2) my access to exercise, 3) my exercise goals, 4) my exercise preferences, 5) my feedback and tracking, and 6) my exercise barriers (10). Open-ended questions provide a unique way of integrating more information that may not have been captured through the other 35 closed-ended questions.

#### 4.2.3 Measurement properties

Dimensionality of constructs was determined using EFA (11). A comparative design was used to test the known-group validity and a test-retest design to test the reproducibility of the PEQ in participants with osteopenia or osteoporosis. All statistical analysis were computed in SPSS version 22.

*Dimensionality:* EFA is used when the researcher has limited knowledge with respect to the dimensionality of constructs (11). The number of dimensions was determined using the eigenvalue greater than one rule and a scree plot (11).

*Known Group Validity:* This type of construct validity measures an instrument's ability to distinguish among distinct groups (15). Group differences were determined using the chi-square test of independence followed by post-hoc analysis. Four hypotheses were identified *a priori* to determine known group validity:

- 1. Participants working full-time are more likely to report time as a barrier to exercise (16,17);
- There is no difference between group-related intervention strategies between older adults (65 and older) and middle aged adults (18);
- Participants from a lower socioeconomic status (SES), less than <\$20,000, are more likely to report finances as barrier to exercise (17,19,20);
- Participants with a safe place to exercise (i.e. proper space to exercise, dry and clean floors, good lighting, etc.) are more likely to be physically active (16);

Chi-square tests were used since variables were nominal, and the phi coefficient (also known as Choen's *w*) was used to calculate effect size. A phi coefficient between 0.10 to 0.30 is considered small, 0.30 to 0.50 moderate, and greater than 0.50 large (21). Question 34 was used to evaluate hypotheses 1 and 4, question 22, hypothesis 2 and question 7, hypothesis 3. In question 7, items marked "yes" were considered safe while "no" and "not sure" considered unsafe.

*Test-Retest Reliability:* This is a measure of stability of an instrument over time through repeated testing and is assessed at two different time points. Participants were given the PEQ at baseline (day 1) and then asked to repeat the same survey again 1 week later (day 7). Seven days were chosen to give participants enough time so they would not remember their answers from the initial assessment. Although the Intraclass Correlation Coefficient is effective for quantifying the reproducibility of continuous data, the PEQ items uses nominal data and was not designed to be a summative score, so the kappa coefficient of Cohen, also known as Cohen's kappa, and weighted kappa were used to estimate the chance-corrected agreement as a measure of test-retest reliability. Cohen's kappa was used for sections one, two, four, five and six, while weighted kappa for section three, which were ordinal items. Since kappa can be problematic to interpret when responses have little variation, percentage agreement was also calculated. Kappa can range from -1 to +1 where 0 represents the agreement that can be expected from random chance and 1 represents perfect agreement between raters (22). A kappa < 0 indicates no agreement, 0.01 - 0.20 none to slight, 0.21 - 0.40 fair, 0.41 - 0.60 moderate, 0.61 - 0.80 substantial, and 0.81 to 1.00 almost perfect agreement (22).

Percentage agreement was considered high if it exceeded 75%, moderate between 40% - 75% and low if less than 40% (22).

#### 4.2.4 Participants

Informed consent was obtained from all participants. Candidates were included if they: 1) provided informed consent, 2) were at least 18 years old, 3) currently had primary osteopenia or osteoporosis (T-score < - 1.0) in any region, and 4) could comprehend, read, and write English. Participants with a cognitive impairment of some severity as to adversely affect the validity of the data were excluded. Patients were recruited from March 13, 2017 to May 3, 2017 at a rheumatology clinic in Hamilton.

#### 4.2.5 Study Procedures

Eligible participants were identified in the clinic by their rheumatologist (JA or AL) and provided introductory information about the study. Potential participants who indicated they would like to hear more about the study were introduced to the research assistant (IR) who went over the study protocol and invited them to complete a questionnaire regarding facilitators and barriers to exercise. Willing participants then signed a consent form and completed a demographic survey and the PEQ either in the clinic or at home. A random subset of participants who completed the survey in the clinic were asked whether they would complete the same questionnaire 7 days later. Those who agreed were given the PEQ in a self-addressed, return envelope. Participants' records were de-identified and distinguished using Personal Identification Digits (PID). A PID was written on each form on the top left corner of the demographic survey, PEQ and return envelopes.

#### Sample Size

Two sample sizes were calculated, one for the known group validity study and the other for the reliability study. A two-tailed test with a power of 80%,  $\alpha = 0.05$  and a dropout of 20% requires at least 114 participants for the comparison study. The sample size required to estimate the test-retest reliability coefficient at a 0.05 level of significance is 46 ( $p_0 = 0.8$ ;  $p_1 = 0.9$ ) (24). A higher  $p_0$  indicates greater reliability, with  $p_0 = 0.8$  indicating the highest acceptable level of reliability (24).

### Questionnaire Completeness

The PEQ was administered to 114 participants for the construct validity test and 49 were completed in the clinic and 65 at home. From the 65 participants that took the PEQ home, 19 did not mail the survey back and a total of 95 surveys out of the 114 were completed. Forty-nine test-retest surveys were administered and 42 questionnaires were returned.

#### 4.3 RESULTS

### 4.3.1 Descriptive Characteristics

General demographic characteristics are summarized in Table 4.1. The mean age of the participants was 66.1 (9.88) with the majority between 50 to 79, specifically, 4% less than 50, 38% between 50 to 64, 43% between 65 to 79, and 15% 80 and over. Fifty-six participants were retired, 22 worked full-time, 9 part-time, and 8 did not work due to disability. Sixty-eight participants self-identified as physically active, 20 as "not active", and 7 were not sure if they were physically active. At the time of administering the PEQ, 87 participants were on medications, most in combination with vitamin D and calcium. The majority of participants were on Prolia (64%) or Actonel (23%). Thirty-nine participants were diagnosed with osteoporosis of the spine and 56 with osteopenia also of the spine; 25 with osteoporosis of the hip and 70 with osteopenia of the hip. All patients were reported to be non-smokers. Eleven participants used mobility devices, 4 used a cane, 3 a cane and a walker, 2 a walker, 1 a wheelchair and a walker, and 1 a wheelchair. There were no differences in terms of age, gender, SES and T-scores of the hip or spine (p > 0.05) between groups that completed the PEQ in clinic and those that competed it at home. More than half of the participants had a prior fracture, some had multiple fractures. Since almost all participants suffered from a different fracture it was difficult to categorize all the fractures.

Table 4.1: General de	mographic charact	teristics of partici	pants that com	pleted the PEO

Characteristics	Total number of participants
Age (years)	< 50 = 4
	50 - 64 = 36
	65 - 79 = 41
	> 80 = 14
Females	87 (92%)
	Single = $9$
	Married $= 61$
Marital Status	Divorced = 11

	Common-law = 4
	Domestic partnership = $1$
	Widow/widower = 9
	Grade school $= 6$
Highest education achieved	High school $= 25$
	College = 30
	University $= 34$
	City = 46
Neighbourhood classification	Suburban = 32
	Rural = 15
	Town = 2
	< \$20,000 = 20
	20,000 - 49,000 = 40
Household income level	50,000 - 79,000 = 17
	\$80,000 - \$99,000 = 8
	> \$100,000 = 5
	No response = $5$
Employment level	Full-time = 22
	Part-time = 9
	Retired $= 56$
	Not working due to disability = $7$
	Not working = 1
T-score, hip(SD)/spine(SD)	-1.89 (0.74) / - 1.87 (1.28)
Prior fracture	61 (64%)

# 4.3.2 Dimensionality

Eigenvalues were calculated and presented in Table 4.2.

Table 4.2: Exploratory	Factor A	Analysis for	r sections 1.	2, 3 and 5 (	n = 95)
			- ~		,

-	Section One: My community support network				
Item	Eigenvalue	% of variance	Kaiser-Meyer- Olkin Measure	Bartlett's Test of Sphericity	p-value (Bartlett's test)
1	1.55	51.64			· · · · · · · · · · · · · · · · · · ·
2	0.86	28.64	0.57	22.03	p < 0.001
3	0.59	19.72			
Section	n Two: My access to ex	xercise			
4	2.46	40.93			
5	1.17	19.52			
6	0.87	14.52	0.64	111.88	p < 0.001
7	0.69	11.43			
8	0.52	8.65			
9	0.30	4.95			
Section	n Three: My exercise g	goals			
10	2.50	35.77			
11	1.15	16.46			
12	0.94	13.48			
13	0.88	12.52	0.63	117.87	p < 0.001
14	0.76	10.87			
15	0.46	6.57			
16	0.30	4.33			
Section	Section Five: My feedback and tracking				
25	2.18	72.52			
28	0.48	16.05	0.70	93.34	p < 0.001

29 0.	34 11.43		

## 4.3.3 Known-Group Validity

The results of the chi square test of independence to determine known group validity are presented

in Table 4.3. Values with p <0.05 were considered statistically significant.

Interpretation Effect Chi Square Raw Values Hypothesis Chi p-value р-Square value of chi square Size Value value (phi)  $(\mathbf{x}^2)$ Participants Full-Not working fulltime Fulltime are more time likely to report Time-19 Accept 15 31.34 < 0.001 < 0.001 time as a barrier hypothesis 1.15 barrier to Timeexercise 3 not a 58 barrier There is no < 65 65 +difference years years between group-Exercise Accept related 19 0.00 0.983 hypothesis 0.99 < 0.001 Alone -26 intervention Yes strategies Exercise between older 29 Alone -21 adults and No middle aged adults Participants < 20 20 +from a lower (SES) (SES) SES are more Reject Financeslikely to report 0.01 0.936 hypothesis 0.92 < 0.001 barrier 3 10 finances as Finances barrier to – not a 17 60 exercise barrier Participants PA – PA with a safe Yes No place to Safe exercise are 0 Accept Place-64 6.25 0.012 < 0.001 more likely to Yes hypothesis 1.04 be physically Safe active Place -24 3 No

Table 4.3: Chi Square values and effect size for known-group validity

## 4.3.3 Test-Retest Reliability

Absolute agreement and Cohen's kappa were calculated for each item in sections 1, 2, 4, 5, and 6 and a weighted kappa for each item in section 3. Results are summarized in Tables 4.4 and 4.4. Reliability was calculated using 42 surveys.

Item	Absolute Agreement %	Cohen's Kappa	p - value	Interpretation		
Section 1:	0			Absolute Agreement	Cohen's Kappa	
1	0.98	0.95	p < 0.001	High	Almost perfect agreement	
2	0.78	0.56	p < 0.001	High	Moderate agreement	
3	0.83	0.53	p = 0.001	High	Moderate agreement	
Section 2:						
4	0.95	- 0.03	p = 0.873	High	No Agreement	
5	0.76	0.23	p = 0.142	High	Slight agreement	
6	0.93	0.84	p < 0.001	High	Almost perfect agreement	
7	0.98	0.90	p < 0.001	High	Almost perfect agreement	
8	0.83	0.64	p < 0.001	High	Substantial agreement	
9	0.90	0.69	p < 0.001	High	Substantial agreement	
Section 4:						
19	0.60	0.56	p < 0.001	Moderate	Moderate agreement	
20	0.83	0.76	p < 0.001	High	Substantial agreement	
21	0.81	0.73	p < 0.001	High	Substantial agreement	
22	0.69	0.59	p < 0.001	Moderate	Moderate agreement	
23	0.57	0.53	p < 0.001	Moderate	Moderate agreement	
24	0.69	0.60	p < 0.001	Moderate	Moderate agreement	
Section 5:						
25	0.88	0.74	p < 0.001	High	Substantial agreement	
28	0.93	0.85	p < 0.001	High	Almost perfect agreement	
29	0.88	0.75	p < 0.001	High	Substantial agreement	
Section 6:						
32	0.71	0.69	p < 0.001	Moderate	Substantial agreement	
33	1.00	1.00	p < 0.001	High	Almost perfect agreement	
34	0.71	0.69	p < 0.001	Moderate	Substantial agreement	
35	0.79	0.66	p < 0.001	High	Substantial agreement	

Table 4.4: Cohen's Kappa calculations for sections 1, 2, 4, 5 and 6 (n = 42)

Table 4.5: Linear v	weighted Kappa	calculations for s	ection 3 (	n = 42)	* CI 95%

Item	Weighted Kappa	p - value	Interpretation
Section 3:			
10	0.68	p < 0.001	Substantial agreement
11	0.40	p < 0.001	Fair agreement
12	0.36	p = 0.002	Fair agreement
13	0.68	p < 0.001	Substantial agreement
14	0.81	p < 0.001	Almost perfect agreement
15	0.79	p < 0.001	Substantial agreement
16	0.86	p < 0.001	Almost perfect agreement

#### **4.4 DISCUSSION**

Despite the challenges in validating a questionnaire that captures different facilitators, barriers and preferences, we were able to provide preliminary support that the PEQ is able to provide valid and reliable information on these aspects. Using the PEQ to understand the factors that influence exercise behaviours may be may be one method to increase adherence in an exercise program.

Factor analysis has many uses, one of which is to establish the number of underlying dimensions between measured variables and latent constructs. Sections one (my community support network) and five (my feedback and tracking) were unidimensional while sections two (my access to exercise) and three (my exercise goals) multidimensional. Factor analysis was not done on sections four (my exercise preferences) and six (my barriers to exercise) since domains could not be quantified. For this reason, the PEQ was not designed as an outcome measure where items can be summed and used to evaluate change, but rather to document dimensions that might influence what type of exercise is likely to most feasible, acceptable and sustainable for individuals with osteoporosis. However, if investigators still want to sum the PEQ, one suggestion to add up individual domains is in Appendix A.4. If internal consistency is calculated for future studies it can only be measured for sections one and five. Factor coherence occurs when items of the subscale are highly correlated to each and not to items in other subscales. However, this may be less likely in a scale like the PEQ. For example, while having social support from friends, spouse and extended family are clearly all-different forms of social support, having one form does not necessarily mean you would have the other. Furthermore, different forms of social support are not necessarily better than one since one type may meet all a person's needs.

Validity has to be established through multiple evaluations of content, construct and where possible criterion validity. In a previous paper, the PEQ demonstrated high content validity of individual items (I-CVI range: 0.50 to 1.00) and moderate to high overall content validity (S-CVI/UA = 0.63; S-CVI/Ave = 0.91) (10), which suggests that the items are perceived as important and clear to respondents and underlies the potential for adequate measurement performance. Known-group validity is a form of construct validity where hypotheses are prespecified and then tested to reflect whether a tool is able to differentiate where differences are expected *a priori*. Where a statistical difference is found, it supports the validity of tool and

where differences are not significant, either the tool/item is flawed, the hypothesis flawed or the power inadequate.

The first hypothesis tested whether participants working full-time are more likely to report lack of time as a barrier to exercise. This premise was strongly supported in the results and the phi coefficient (effect size) suggested a strong difference between these two groups supporting the validity of this item. Since this item showed that people who were working reported time as a barrier more often than individuals that did not work full-time, this supports the intention of this item to measure time demands. There was a significant difference between constructs, the results provide evidence of construct validity of that item and researchers can be confident that this question measures what it claims to. This item may help clinicians identify working individuals who have difficulty balancing exercise and work demands. Future work should also determine to what extent these patient's perceptions are accurate, or if other underlying factors are causing patients to perceive a lack of time that do not, in fact, exist. In many cases, perceived lack of time may not reflect an actual lack of time and time management classes or strategies to assist participants with integrating exercise into a busy schedule may be necessary (21).

The second hypothesis suggested that there is no difference between exercise group sizes between older adults and middle-aged adults. This study found this theory was supported and that item 22 measures the construct it claims to be measuring. Although previous papers suggested that older adults prefer to exercise alone rather than in a group-based setting, recent findings challenge this literature, and new studies have found older adults prefer group-related interventions among people their own age (18). One reason why older adults may have suggested solitary exercise programs in previous literature is their perceived view that exercise classes tend to be populated by individuals younger than them (18). Beauchamp et al (2007) also found older adults prefer exercising in a group setting with individuals their own age (18) and adherence levels tend to be far superior when done in exercise groups compared to alone (25–27). Future exercise designs should use the PEQ to determine group size preferences for an exercise program and based on the majority, design an exercise program where participants either exercise alone or with other individuals. Since older adults prefer to exercise with people their own age, having an instructor of a similar age to the participants may also help participants feel more comfortable to exercise.

Finances have been listed as one common barrier to exercise in people with osteoporosis (2). We hypothesized that participants from a lower SES would report cost as a barrier, however, found no difference between these two groups. Although the hypothesis was not validated, we do not believe the item itself is flawed since there is strong support in the literature and evidence from participant's feedback during the development of the PEQ. We also do not believe the hypothesis is flawed since a number of papers support the relationship between income level and physical activity and found participants from a higher SES are likely to be more active (16,17,19,20). It is possible that neither the item nor the hypothesis is unreliable since more than half of the participants were retired or not working due to disability and reported an income less than \$50,000, possibly an income level lower than before their retirement, it may have skewed their real SES. Other possible explanations may be that social supports available through the Canadian government for low-income families can reduce the burden of access to exercise facilities and alleviate some of the costs regarding exercise programs. This is still an important item to evaluate and researchers and clinicians should be aware of subsidies that participants may or may not have that can influence financial costs in terms of exercise.

Environmental correlates of physical activity have gained attention over the last decade and include accessibility to a facility, aesthetic attributes, and safety features (16) and our last hypothesis strongly corroborates these findings. This validity of this item is important, since the results provide evidence that the item measures what it is supposed to. Environment is hypothesized to influence behavioural intentions based on a meta-analysis that found individuals with a more positive attitude toward their environmental surroundings to be more likely to accomplish their intended behaviour (28). Thus, environmental barriers should not be ignored when designing future exercise programs and promoting adherence. Designing exercise facilities that are safe and esthetically pleasing may be a simple way to encourage exercise behaviours and the PEQ can be used to identify this.

The known-group validity hypotheses were chosen to reflect the most commonly reported facilitators and barriers. Even though only 4 items were used to determine the known-group validity, these preliminary results indicate the PEQ is a valid tool capable of detecting the facilitators, barriers and preferences to exercise in the osteoporosis population.

The PEQ demonstrates moderate test-retest reliability with some domains having better reliability than others. There were 12 items with a kappa >0.70 items and 9 items with kappa <0.60. Although some items had a low kappa score this does not necessary indicate a low confidence rating in the item if it has a high absolute agreement score. An items reliability may be questioned when both the absolute agreement and the kappa score are low. In the PEQ absolutely agreement ranged from moderate to high, with most items scoring high.

The reliability of each item for section one ranged from moderate to almost perfect agreement. Questions 2 (healthcare's attitude toward exercise) and 3 (friends/families attitude toward exercise) had the lowest scores and demonstrated moderate agreement. The low reliability of these questions might indicate a hidden problem. It has been reported that 79% of Canadians see a physician more frequently than any other healthcare provider, however, physicians and nurses have the least knowledge and confidence regarding exercise and exercise prescriptions compared to other healthcare provider (29). Although physicians may want to encourage an active lifestyle, their lack of knowledge and confidence to prescribe exercise may have been reflected in the respondents' answers. About 28% of participants selected a different answer the second time and there was no pattern to the selection process; a few participants selected "not sure" the first time and "yes" the second, while others selected "yes" the first time and "no" the second. A similar situation may be happening with the respondents' family and friends. A low score for question 3 may indicate that the respondents' family and friends may not believe exercise is important and may fail to convincingly persuade active participation in exercise.

The reliability of each item for section two ranged in some questions from "no agreement" to "almost perfect agreement". Questions 4 and 5 regarding the location of an exercise facility and transportation demonstrated "no agreement" and "slight agreement", respectively. In question 4, the absolute agreement calculation showed 98% of participants selected the same answer in both rounds and the reason for the discrepancy between the unadjusted level of agreement and kappa may be known as the Kappa Paradox. In this paradox analysis may show a high value for the absolute agreement and a drastically low kappa score (30). Although a maximum attainable kappa (k<sub>m</sub>) is suggested to fix this imbalance, it may not solve the paradox (30). Thus, even though question 4 has a low kappa, this does not represent the true precision of the item. Item 5 also demonstrated low reliability. The absolute agreement

calculation showed 77% of respondents selected the same answer in both rounds. This item may be indicating that transportation needs fluctuate on a daily bases. The majority of respondents were over the age of 60 and depended on family or friends to assist them. Transportation has been listed as one of the major barriers to exercise in older adults and in the osteoporosis population (31,32). Although the reliability of this question is low, it is important to examine the dynamics of this barrier.

Weighted kappa was used to determine the reliability of each item in section three, which ranged from fair to almost perfect agreement. The lowest subscale scores were in questions 11 (able to walk longer) and 12 (more flexible). A little less than a third of participants (31%) were inconsistent with their answers for question 11, and 17% for question 12. From the participants that answered question 11 differently from round 1 to 2, 38% of this 1/3 selected "very important" the first time and "somewhat important" the second, and 15% of this same 1/3 selected "very important" the first time and "not important" the second. More than half of participants that changed their answers decided that this goal was no longer important compared to other goals. Similarly, more than half of participants (57%) of those that answered question 12 differently (17%) indicated an option of higher importance the second time. Participants may have had more time to think about their goals and reflect on each item the second time since questionnaires were completed at home. However, we can discount that the length of the questionnaire discouraged careful consideration of each item or that the item was unclear.

Section four had a reliability score for each item that ranged from moderate to substantial agreement. Question 23 regarding learning proper techniques had the lowest reliability score, which was expected since it had nine options. For this item participants selected one or two more items the second time. Overall, respondents' answers were not very different from the first round to the second, differing by just one or two choices.

Section five regarding feedback and tracking had the highest reliability, and each item ranged from substantial agreement to almost perfect agreement. The majority of participants that selected "yes" as a choice for one answer also selected "yes" for the other two questions. The same pattern was seen when participants selected "no".

The last section, regarding barriers to exercise had a reliability item score that ranged from substantial agreement to almost perfect agreement. There was a general trend where, the second time,

participants checked one or two additional barriers. This also could have happened because respondents had more time to think about their barriers while completing the PEQ the second time.

#### 4.5 STRENGTHS AND LIMITATIONS

Strengths of this paper include an adequate sample size that was powered, all patients had a diagnosis from a single rheumatologist and a single independent evaluator conducted all the data collection. Although this paper conformed to the highest standards of work, it is not without limitations. Our test-retest sample size was estimated at 46, however only 42 surveys were returned. It is unlikely that 4 more responses would have changed our conclusions, but some imprecision in our estimates is possible since we had a 91% return rate (CI 0.8 - 0.9). This study also recruited more women than men, which could potentially impact the generalizability of the findings to males. Lastly, many participants were retired or not working due to disability and their reported earnings may have not reflected accurately their true SES.

#### **4.6 CONCLUSION**

In this paper, the PEQ demonstrated sufficient known-group validity and moderate to high testretest reliability. In addition factor analysis revealed sections one and five were unidimensional while sections two and three multidimensional. Implications of this measure could be useful in the development of client-centered exercise interventions for people with osteopenia or osteoporosis. The PEQ should be evaluated for additional measurement properties, and most importantly, for its usefulness in exercise prescription and adherence.

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#### 4.8 APPENDIX A.4

#### Scoring the PEQ

Scoring the PEQ may be difficult since adding results from a unidimensional and

multidimensional section does not give a useful value, however, individual domains can be scored with a minimum score of 0. Section one has three questions and can have a maximum score of 3, where "no", "not sure", and "not applicable" receive a score of 0 for each item, and "yes" a score of 1. If all three items are marked "yes" the score is 3, if only two are marked "yes", the score is 2, and if only one is marked "yes" the score is 1. A score of 3 indicates a strong support network and suggests an individual is more likely to participate in exercise activities. Section two can have a maximum score of 6 and uses the same scale as

section one. A higher score suggests participants have access to an exercise facility, a good indication of exercise participation. Section three can have a maximum score of 14, were "not important" and "not applicable" receive a score of 0 for each item, "somewhat important" a score of 1, and "very important" a score of 2. Higher scores indicate participants do not have a specific exercise goal, and may be exercising for overall health benefits. Lower scores should be individually studied to determine the respondents most important exercise goal. Section five can have a maximum score of 3, where "no" is given a score of 0 and "yes" a score of 1. A higher score indicates participants would like to participate in feedback and tracking methods, while a lower score, less feedback. Sections four (my exercise preferences) and six (my exercise barriers) should not have an overall score. If one person had 1 barrier to exercise and another person had 3 barriers to exercise, an investigator cannot conclude that a person with more barriers is less likely to exercise. The person with one barrier who is wheelchair bound and lives in an area with reduced accessibilities to exercise facilities would have a harder time participating in regular physical activity compared to someone with more manageable barriers such as "lack of time", "not enjoying the exercise", and "feeling bored". Facilitators and barriers in the PEQ should be examined by studying each item instead of quantifying them. The best way to interpret sections four and five is to code the data using a sequence of 0s and 1s. For example, question 19 in section 4 has 6 options (home, gym, mall, community centre, outdoors, other). Options without a checkmark should receive a value of 0, while options with a checkmark should receive a value of 1. If a participant indicates they would like to exercise at home or the gym the sequence the investigator would enter into an MS Excel file for that patient would be: "1,1,0,0,0,0". Then the investigators can determine the number of people that selected that sequence. The sequence that appears the most times will identify, in the case for question 19, the location participants would feel most comfortable exercising. Sections 4 and 6 cannot be added up to a total score but assessed at individual bases.

Chapter Five: Future Direction and Concluding Remarks

### **Future Directions and Conclusion**

#### **5.1 SUMMARY**

This thesis is focused on the development, validation and reliability of a new tool, the Personalized Exercise Questionnaire (PEQ), a new tool designed to measure the facilitators, barriers and preferences to exercise in the osteopenia and osteoporosis population.

The summary of the systematic review categorized the most commonly reported facilitators and barriers to exercise, and identified the methods used in randomized control trials (RCTs) to promote exercise adherence in the osteoporosis population. Fifty-four RCTs were examined and no one facilitator was more frequently reported than the other while the most commonly reported barriers were lack of time and transportation. Based on this extensive review, a list of items were created to classify participants' motivators, barriers and preferences to exercise; additional items were generated from the literature from other populations similar to the osteoporosis group. Through qualitative methods, items were reworded and improved until the tool consisted of 6 domains and 38 questions (35 categorical questions and 3 open-ended items). The content validity of the tool was high for individual items and overall moderate to high for the entire tool; this thesis also established sufficient known-group validity and moderate to high test-retest reliability of the PEQ in the osteoporosis population. The PEQ appears to possess sufficient validity and reliability to warrant its use by researchers and clinicians.

### **5.2 STUDY STRENGTHS AND LIMITATIONS**

The strengths of this thesis include: (1) using both quantitative and qualitative methods to develop and design the PEQ, (2) using multiple levels of experts (healthcare professionals, graduate students and patients with osteopenia or osteoporosis) to assess the importance and clarity of each item and (3) validating the tool using a couple of measures (i.e. content and construct validity). Experts were recruited from multiple areas in Ontario (a large city, small cities and rural areas) to create a more comprehensive tool that encompassed facilitators, barriers and preferences from several regions. During the development phase of the PEQ (Chapter 3) we also recruited more males than females, to compensate for the osteoporosis literature that recruits more females, in an attempt to include facilitators and barriers applicable to both genders. One of the main advantages of this measure is that it can be completed at home reducing the burden of transportation costs to the clinic, on the patient, and the economical cost of

administration by healthcare professionals. Despite these strengths, our study had its limitations, in particular, in the reliability study, with only 42 returned surveys; however, it is unlikely that 4 additional assessments would have changed the results. We also recruited more women than men (Chapter 4), and our enrolled population was mostly from the Hamilton region, a small area in Southern Ontario, which may impact the generalizability of the results. Lastly, the development of the PEQ relied only on the English literature and feedback from English speaking participants, healthcare professionals and clinicians. At risk groups such as Native Americans or older adult refugees may experience other barriers not listed in the PEQ, however, the open-ended questions may capture these factors.

#### **5.3 FUTURE DIRECTIONS**

Our study findings have significant implications in the field of exercise and exercise adherence even though it only scratches the surface of potential ways to increase activity levels in the osteoporosis population. Next steps should test the PEQ in the osteoporosis population and identify some of the major facilitators and barriers and assess different methods to leverage the motivators and limit the obstacles to exercise. Some barriers, such as being wheelchair bound or with a mental disability, would require researchers and clinicians to work with their participants to find unique methods to mitigate these barriers in an exercise program. Studies using the PEQ to customize programs that would determine the effectiveness of this approach to improve exercise adherence would require large clinical trials. It is also important to train and educate researchers and clinicians to use the PEQ and help them understand the different factors that affect adherence. In order to see the full benefits of the PEQ, it is important that researchers and clinicians work together with the participants to find solutions to these factors that affect adherence. We also believe the PEQ has implications at the institutional level. Educating exercise companies such as the YMCA, Goodlife Fitness, Wynn Fitness, etc. on trends about exercise preferences or how to use the PEQ with individual clients may help improve access to facilities and make them friendlier toward vulnerable populations.

The PEQ was developed and tested using the southern Ontario population who were mainly Caucasian, so its validity and reliability in other ethnic or religious groups are unknown and geographical factors that affect exercise adherence should also be tested. For example Native Americans are a vulnerable population prone to a number of health comorbidities, experience a number of health disparities and might

have limited exercise facilities, which could be validated using the PEQ to increase their exercise adherence. Although the PEQ was developed specifically for the osteopenia and osteoporosis population, literature from the osteoarthritis and older adults populations was also used to create the tool. The PEQ should also be tested in these populations to determine its usefulness in identifying factors that affect adherence to exercise.

Ultimately, the PEQ is a tool that may be one method to increase exercise behaviours in patients with osteoporosis and studies in both the research and clinical setting should continue to explore the applications of this tool to enhance their understanding in exercise design and adherence.

Appendix A

# Personalized Exercise Questionnaire (PEQ)

# PLEASE READ THESE INSTRUCTIONS BEFORE STARTING:

This survey was created to better <u>understand</u> your <u>exercise needs</u> and <u>goals</u>. By completing this survey you will help us understand some of the difficulties you face in an exercise program. This information will be used to help us create better exercise/ physical activity program for you.

There are <u>6 sections</u> and <u>38 questions</u>. Please complete <u>ALL</u> questions relevant to you. All answers will be kept strictly confidential and never associated with your name

SECTION ONE: My Support Net	twork			
	No	Not Sure	Yes	Not Applicable
1. I prefer someone to supervise/ assist me with an exercise:				
If <b>YES</b> , under a:				
<ul> <li>Healthcare professional (e.g. physiotherapist)</li> <li>Personal Trainer</li> <li>Other:</li> </ul>				
2. I have a healthcare provider (e.g. physician, physiotherapist, nurse, etc.) with a good attitude toward exercise that encourage me to be active:				
3. I have friends/family with a good attitude toward exercise that encourage me to be active:				

SECTION TWO: My Access to Exercise				
	No	Not Sure	Yes	Not Applicable
4. I have a place to exercise (indoor or outdoor) at home, place of work or near my home/work place:				
If <b>YES</b> , how far:				
<ul> <li>□ At home or at work</li> <li>□ &lt; 5 km (&lt; 3 miles)</li> <li>□ 5 - 10 km (3-6 miles)</li> </ul>				
5. I am able to get to an exercise site on my own: (Check "Not Applicable" if you exercise at home)				
If <u>NO</u> , who could you ask:				
<ul> <li>Family member/partner</li> <li>Friend</li> <li>Other:</li> </ul>				
6. I have transportation to an exercise site: (Check "Not Applicable" if you exercise at home)				
If <b>YES</b> , type of transportation:				
<ul> <li>Bike</li> <li>Motor Vehicle (e.g. car)</li> <li>Public transportation</li> <li>Walking</li> </ul>				
7. I have a safe place to exercise: (e.g. proper space to exercise, dry and clean floors, good lighting, etc.				
8. I have an encouraging place to exercise: (e.g. pleasant people that motivate me)				

	No	Not Sure	Yes	Not Applicable
9. I have an exercise location that is free of cost or reasonably priced (including parking fees):				

# **SECTION THREE:** My Exercise Goals

# How important are the following <u>GOALS</u> to YOU in an exercise program?

	Not Important	Somewhat Important	Very Important	Not Applicable
10. Feel less tired				
11. Be able to walk longer				
12. Be more flexible				
13. Have better balance				
14. Fall less often				
15. Have less pain				
16. Increase muscle strength				

# 17. What is your MOST important exercise goal?

# **SECTION FOUR:** My Exercise Preferences

18. Please list up to 3 things that <u>HELP</u> you to exercise more often:

# 19. Where would you like your exercise program to be? (Check ALL that apply)

- □ Home
- Gym (e.g. YMCA/YWCA, Goodlife Fitness, Wynn Fitness, etc.)
- 🗆 Mall
- □ Community Centre
- Outdoors (e.g. parks, trails, sidewalks, etc.)
- □ Other:\_\_\_\_\_

20. What is the best time for you to exercise? (Check ALL that apply)

- □ Morning (between 6:00 am to 12:00 pm)
- Afternoon (between 12:00 pm to 6:00 pm)
- Evening (between 6:00 pm to 11:00 pm)
- 21. What is your preferred exercise schedule? (Check ALL that apply)
- □ Fixed time (same class offered at same time during the week)
- □ Multiple drop-in times (same class offered at different times of the week)
- $\Box$  On my own time
- 22. What is your preferred exercise class size? (Check ALL that apply)
- □ I prefer to exercise alone
- □ With a partner/trainer
- □ Small group (less than 10 people)
- Large group (more than 10 people)
- Does not matter

23. How would you like to learn proper exercise technique? (Check ALL that apply)

- Taught by a healthcare professional (e.g. physiotherapist, nurse, etc.)
- □ Taught by a trainer/health club staff
- □ Learn on my own from an exercise video
- □ Learn on my own from a website with pictures
- □ Learn on my own using an app
- □ Learn on my own using a print handout
- ☐ Have a friend teach me
- □ Have another person with osteoporosis teach me
- $\Box$  None of the above

24. What level of exercise are you comfortable doing? (Check ALL that apply)

- □ Easy to perform
- □ Challenging to perform (i.e. "I like a challenge")
- $\Box$  Slow paced exercises
- □ Fast paced exercises
- □ Easy to remember

# SECTION FIVE: My Feedback and Tracking

- 25. I would like to receive feedback about my progress:
  - □ YES
  - $\Box$  NO

If <u>YES</u>, by: (Check ALL that apply)

- 🗆 Email
- $\Box$  In person
- Social media (e.g. Twitter, Facebook, etc.)
- $\Box$  Phone call
- □ Text message

If you answered <u>YES</u> to question 25, please complete questions 26 and 27.

If you answered <u>NO</u> to question 25, please skip to question 28.

26. What type of feedback would you like to receive? (Check ALL that apply)

- □ Regarding my exercise progress and future improvements
- □ Regarding proper exercise techniques
- □ Other:\_\_\_\_\_

27. How often would you like to receive feedback about your exercise progress? (Please check only **ONE** answer)

- □ Daily
- □ Weekly
- □ Monthly
- □ Yearly

28. I would like to give feedback on the exercise program:

- □ YES
- □ NO

If <u>YES</u>, by (Check ALL that apply):

- 🗆 Email
- $\Box$  In person
- Social media (e.g. Twitter, Facebook, etc.)
- □ Phone call
- □ Text message
- 29. I would like to track my exercise progress:
  - □ YES
  - $\Box$  NO

If **YES**, using (Check ALL that apply):

- □ Cellphone/mobile
- □ Diary/Log book
- □ Wearable technology (e.g. Fit Bit, pedometer, watch etc.)
- □ Other:\_\_\_\_\_

# SECTION SIX: My Barriers to Exercise

30. Do you have things that <u>STOP</u> you from exercising?

- □ Yes
- □ No

If **YES**, how often does it stop you from exercising: (Check only **ONE** answer)

- AlwaysVery oftenSometimes
- □ Rarely

31. Please list up to 3 things that <u>STOP</u> you from exercising more often:

32. I do not exercise as often as I like because: (Check ALL that apply)

- I do not like exercise
- □ I do not want to <u>fall</u>
- I do not want to <u>injure</u> myself (e.g. breaking a bone or bruising)
- □ I feel <u>pain</u> when I exercise
- □ I feel <u>bored</u> when exercising
- □ Other:
- $\hfill\square$  None of the above

33. I do not exercise as often as I like because I have difficulty: (Check ALL that apply)

- □ Understanding the exercise
- □ Performing the exercise (i.e. I do not know how to exercise safely)
- □ Other:
- $\Box$  None of the above

# 34. I do not exercise as often as I like because I do not have: (Check ALL that apply)

- $\Box$  A place to exercise
- □ Confidence (e.g. I feel self-conscious about my body)

\_\_\_\_\_

- □ Finances
- □ Mobility (e.g. limited movements due to pain)
- □ Proper quality of sleep
- □ Transportation
- Time (e.g. family priorities, work, etc.)
- □ Willpower/motivation
- □ Other:
- $\Box$  None of the above

35. Do weather conditions stop you from exercising as often as you like? (Check only **ONE** answer)

- □ Always
- □ Very often
- □ Sometimes
- □ Rarely
- □ Never

# 36. I do not exercise as often as I like because I have medical conditions such as: (Check ALL that apply)

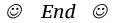
- Arthritis (e.g. hips, knees, etc.)
- **Cognitive concerns** (e.g. Alzheimer, Dementia, Parkinson, etc.)
- Heart condition (e.g. angina, heart failure, etc.)
- ☐ Kidney disease (e.g. dialysis)
- Lung disease (e.g. asthma, COPD, etc.)
- ☐ Mental health issues (e.g. anxiety, depression, etc.)
- $\Box$  Other:
- $\Box$  None of the above

# 37. If you had fewer barriers would you spend more time exercising? (Please check only **ONE** answer)

- □ Yes
- 🗆 No
- $\Box$  Not sure

# 38. Please check any mobility aids that you normally use:

- □ Cane
- □ Walker
- □ Crutches
- □ Wheelchair
- □ Other:\_\_\_\_\_
- □ None



## Appendix B

## **Demographic Survey**

Please complete the following information:

- 1. What is your current age?
- 2. What is your gender?
  - $\square$  Male
  - □ Female
  - □ Other: \_\_\_\_\_
- 3. What is your current marital status?
  - □ Single
  - □ Married
  - □ Divorced
  - $\Box$  Common-law
  - □ Domestic partnership
  - $\Box$  Widow/widower
- 4. What level of education did you complete?
  - $\Box$  Grade school (grade 1 to grade 8)
  - $\Box$  High school (grade 9 to grade 12/13)
  - □ College
  - □ University
  - Graduate school (e.g. Master, Ph.D., etc.)
  - □ Professional school (e.g. medical school, law school, etc.)
- 5. What is your current level of employment?
  - □ Full-time
  - □ Part-time
  - $\Box$  Not working due to disability
  - $\Box$  Retired
- 6. What is your neighbourhood/dwelling classification?
  - $\Box$  Rural area
  - $\Box$  Suburban area
  - □ City
  - □ Other:\_\_\_\_\_
- 7. What is your current income (per year)?
  - □ <\$ 20,000
  - □ \$20,000 to \$50,000
  - □ \$50,000 to \$80,000
  - □ \$80,000 to \$100,000
  - □ >\$100,000
- 8. Do you currently consider yourself physical active?
  - $\Box$  Yes
  - 🗆 No
  - $\Box$  Not Sure

# Appendix C

# PARTICIPANT INFORMATION SHEET

# Title of Study: Reliability and validity study of the facilitators and barriers to exercise questionnaire

Student Investigator: Isabel B Rodrigues, B.Sc., M.Sc. (candidate) Local Principal Investigator: Dr. Joy MacDermid, PT, Ph.D Department of Rehabilitation Sciences McMaster University Hamilton, ON, Canada (905)-865-7426 E-mail: rodrigib@mcmaster.ca

You are being invited to participate in a research study conducted by Isabel B Rodrigues because you have osteoporosis or osteopenia.

In order to decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study. Please take your time to make your decision. Feel free to discuss it with your friends and family, or your family physician. If you would like more information regarding the project please contact Isabel Rodrigues at (905) - 865 – 7426.

# WHY IS THIS RESEARCH BEING DONE?

Many studies have shown exercise to be beneficial in maintaining or increasing bone mineral density and muscle mass. Although there are benefits to being physically active, many do not exercise, and 50% of those registered in an exercise program drop out within the first 6 months. The facilitators and barriers to exercise in people with osteoporosis are currently not known. There is no survey that measures these important factors.

# WHAT IS THE PURPOSE OF THIS STUDY?

To assess the reliability and validity of a new survey that measures individuals' facilitators and barriers to exercise.

# WHAT WILL MY RESPONSIBILITIES BE IF I TAKE PART IN THE STUDY?

If you volunteer to participate, you will be asked to answer a survey on your facilitators and barriers to exercise. The survey will take approximately 20-30 minutes to complete.

## WHAT WILL MY RESPONSIBILITIES BE IF I TAKE PART IN THE STUDY?

If you volunteer to participate, you will be asked to answer a survey on your facilitators and barriers to exercise. The survey will take approximately 15-20 minutes to complete.

You may also be asked to complete the surveys again after approximately 1 week.

# WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

There are no foreseeable risks associated with this study. You may feel worried about your responses. There are no right or wrong answers and your responses will be kept confidential so you should not worry about this.

# HOW MANY PEOPLE WILL BE IN THIS STUDY?

There will be a total of 114 participants in the study. A subset of 57 participants will be asked to do the survey again within 2 weeks.

# WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?

We cannot promise any personal benefits to you from your participation in this study. The results of this study may benefit society and the scientific community by providing health care providers with a tool that can identify the facilitators and barriers to exercise in people with osteoporosis or osteopenia.

# WHAT INFORMATION WILL BE KEPT PRIVATE?

Your data will not be shared with anyone except with your consent or as required by law. All personal information such as your name and e-mail address will be removed from the data and will be replaced with a number. A list linking the number with your name will be kept in a secure place, separate from your file. The data, with identifying information removed will be securely stored in a locked office in the research laboratory.

For the purposes of ensuring the proper monitoring of the research study, it is possible that a member of the Hamilton Integrated Research Ethics Board may consult your research data. However, no records which identify you by name or initials will be allowed to leave the hospital. By signing this consent form, you or your legally acceptable representative authorize such access.

If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your specific consent to the disclosure.

## CAN PARTICIPATION IN THE STUDY END EARLY?

If you volunteer to be in this study, you may withdraw at any time. You have the option of removing your data from the study. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

## WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

You will not be paid to participate in this study. **WILL THERE BE ANY COSTS?** 

There are no costs associated with this study.

## IF I HAVE ANY QUESTIONS OR PROBLEMS, WHOM CAN I CALL?

If you have any questions about the research now or later, please contact: Isabel B Rodrigues, Master's Candidate at 905-865-7426

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, Hamilton Integrated Research Ethics Board at 905.521.2100 x 42013.

## I understand the terms of participation as outlined above and by signing below I am giving my consent to participate in the study. I will receive a copy of this consent form.

I would like to receive a summary of the study's results. Yes	es No
---	-------

*If yes, where would you like the results sent:* 

Email: \_\_\_\_\_

Mailing address: \_\_\_\_\_

Name of Participant (Printed)	Signature	Date
Consent form explained in person by:		
Name and Role (Printed)	Signature	Date