

WALKING WITH MEANING

by

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Abstract

Today, increasing physical activity is being promoted as one of the most effective interventions for enhancing overall health and quality of life, especially for older people. Research has clearly shown that adequate exercise reduces risk for certain diseases, lowers the risk for impaired mobility and prevents cognitive decline. Despite the overwhelming amount of evidence regarding the benefits of exercising regularly, many older adults do not engage in this form of physical activity. Given our need to better understand how to promote healthy aging in this growing population, there is an emerging body of research exploring the question of why activity levels are low among older people and how they can be encouraged to become more active. However, people who have been diagnosed with dementia have not been included in this research. In this already under-active age group, it is extremely important to understand what drives or motivates the older adult with dementia to be physically active. In order to understand the drive we must first understand the significance of physical activity for this group of people. Therefore, the purpose of this study was to explore and understand the meaning of physical activity for older adults who have been diagnosed with dementia.

This study was a secondary analysis of data drawn from a larger qualitative investigation on the everyday lives of people living with early dementia. Purposeful sampling was used for this secondary analysis; participants were selected because their interviews from the original study had some discussion on the subject of physical activity. The final sample was comprised of 12 participants between the ages of 65 and 86 years. The findings of this study show that older adults with dementia are attracted to physical activity and perceive numerous physical, emotional and social benefits from their involvement, even in the face of aging and dementia-related health changes.

The major finding in this study on physical activity in older adults with dementia was that walking was becoming increasingly meaningful to them. The finding that walking may be an important way for people with dementia to stay involved in physical activity is discussed.

Preface

Ethical approval for this study was obtained from the Behavioral Research Ethics Board (BREB) of the University of British Columbia (certificate number is H05-80330)

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1 Introduction

The professional and lay literature includes innumerable recommendations regarding the need for increased physical activity on the part of adults. Today, increasing physical activity is being promoted as one of the most effective interventions for enhancing overall health and quality of life, especially for older people. Research has clearly shown that adequate exercise reduces risk for certain diseases, lowers the risk for impaired mobility (Bonsdorff et al., 2009) and prevents cognitive decline (Prohaska et al., 2009).

However, despite the overwhelming amount of evidence regarding the benefits of exercising regularly, many older adults do not engage in this form of physical activity. Statistics Canada's Canadian Health Measures Survey found that the majority of Canadian adults' waking hours were sedentary. The percentage of adult Canadians reaching the recommended physical activity level is 17% for men and 14% for woman, and the highest level of inactivity is among those over 60 years of age (Colley et al., 2011).

This age group is growing rapidly. Projections show that within the next few years Canada will have more seniors than children. In 2001, there was one senior for every 8 of the overall Canadian population, but by 2040 these numbers will increase and we will see one senior to every four Canadians.

Given our need to better understand how to promote healthy aging in this growing population, there is an emerging body of research exploring the question of why activity levels are low among older people and how they can be encouraged to become more active. However, people who have been diagnosed with dementia have not been included in this research.

This is an important gap in the literature. As the population ages, the number of people who are living with dementia is growing rapidly. According to a recent report by the Alzheimer

Society of Canada, by 2040 there will be over 1.1 million Canadians with dementia with a projected incidence of 257, 800 new cases a year or a new case diagnosed every two minutes. A majority of these people will live in the community for many years. Given the potential health benefits of physical activity, it is important to extend research to include the experiences of these people with dementia who are living at home.

In summary, the following facts are clearly evident in the literature: seniors in Canada are the fastest growing population group; older adults are less active than any other group; and dementia in older adults is increasing. Older adults with dementia can have limited physical activity because their disease can affect motor function. Gait disturbances, rigidity, impaired balance and slower movements have all been observed and reported in dementias (Miller, 2011), although it is unclear how this impacts on their experience of physical activity. In this already under-active age group, it is extremely important to understand what drives or motivates the older adult with dementia to be physically active. In order to understand the drive we must first understand the significance of physical activity for this group of people. This is an under-researched area. Therefore, the purpose of this study is to explore and understand the meaning of physical activity for older adults who have been diagnosed with dementia.

2 Literature Review

2.1 Benefits of physical activity and the risks of inactivity

There is a positive relationship between healthy aging and physical activity. With aging physical limitations can affect the activities of daily living, therefore having good daily functioning is dependent on being physically active well into later life. No matter what age, health status or fitness level, all adults can benefit from physical activity. Strength, endurance and flexibility can improve at any age by becoming more active (Health Canada, 2010). Physical activity includes being active in everyday life; taking part in activities such as gardening, taking walks, playing games, occupational and volunteer work, dancing, and doing house work all influence well being (Ritchey, Ritchey & Dietz, 2001; WHO, 2010).

Physical functioning and mobility influence independence and are essential to the quality of life of an older adult. Loss of independence can be related to poor ability to reach, carry, bend and lift (Canada Physical Activity Guide, 2010). Inactivity in the older adult, such as sitting or lying for extended periods of time, affect physical functioning and can cause muscle loss, bone fragility (Karinkanta et al., 2007), loss of flexibility and balance (Luukinen, Lehtola, Jokelainen, Vaananen-Sainio, & Lotvonen, 2006), increase the risk of falls (Tinetti, 2003), thus leading to serious health risk.

The benefits of regular physical activity in the older adult are well documented; as well as slowing functional decline (World Health Organization, 2010), improving muscle strength and (Taylor et al., 2004; Tremblay et al., 2007), reducing falls (Litt, Kleppinger, & Judge, 2002) it can improve sleep and mental health (Dubbert, Cooper, Kirchner, Meydrech, & Bilbrew, 2002; Taylor et al., 2004.), help maintain neurocognitive function, (Nied & Franklin, 2002), improve

energy, and help to maintain healthy weight (Health Canada, 2010). Older adults who are more active compared to less active adults have lower rates of coronary artery disease, diabetes, high blood pressure and stroke (WHO, 2010).

2.2 Barriers to physical activity in older adults

There is often only a vague awareness amongst older adults that exercise is good for overall health and that health benefits can be gained at any age. Many adults experience barriers to exercise that range from unpleasant sensations to lack of time. The older adult population has these plus other unique barriers to physical activity. Older adults may think they are too old to exercise or that starting an exercise regime later in life has little point. Some believe that they do not have enough energy and they should rest and save their energy instead of using it. There is a frequently a misconception that exercise must be strenuous to benefit health. There are older adults who think that exercise can cause falls and increase the risk for fractures or feel that poor health and limitations related to chronic disease and disability prevent them from activity (Brawley, Rejeski & King, 2003; Clark, 1999). Many people are not willing to change their exercise habits (Luukinen et al., 2006) claiming they have a lack of time, lack of skill (Brawley et al., Rejeski & King, 2003) or a lack of knowledge on how to begin an exercise program (de Groot & Fagerstrom, 2011). In 1998 the Canadian Physical Activity Benchmark Report identified the major barriers to physical activity in the older adult to be lack of time, lack of energy, fear of unfamiliarity, low motivation, concerns with weather and with the environment such as having no places to rest.

Older adults, especially older women, are less likely to take part in an activity outside if their neighborhood is perceived to be unsafe, the weather to be poor or if the streets and sidewalks are in poor condition (Brawley et al., 2003). There is a strong association between

social support and the belief in one's ability to perform physical activity especially in older women (Schutzer & Graves, 2004). Social support and encouragement are needed for older women to maintain an exercise program (Cousins, 1995). Social support activities such as driving the elder to an exercise facility, phoning to see how the program is working, sharing information on upcoming events that involve exercise and joining the elder in walks or exercise may enhance efficacy (Resnick, Orwig, Magaziner, & Wynne, 2002). Women in exercise programs develop social networks and get encouragement to continue to stay active (Cousins, 1995). Social supports can come from many different people such as family, neighbors, or friends. Efficacy is also strengthened by successful performance in an activity, verbal encouragement from a trustworthy source, seeing others of similar age partake in exercise (Resnick et al., 2002), as well as experiencing feelings of pleasure and satisfaction (Schutzer & Graves, 2004). Physical activity programs that are associated with a higher attendance level and uptake are programs that are less expensive, convenient, at least a moderate intensity level and for women include a social aspect.

2.3 The effects of physical activity on cognitive function

There is mounting research showing that increased physical activity has a positive effect on cognition in older adults. Many of the available studies show evidence that people who are more physically active experience less cognitive decline in later life than those people who are more sedentary. Studies in this area mainly focus on the role physical activity has on preventing cognitive decline over time. All studies reviewed classified physical activity into three categories, no physical activity, moderate exercise (< 3 times a week) and high exercise (>3 times a week). Studies assessed cognition using either the Mini-Mental State Examination (MMSE) or a 6 item Cognitive Impairment Test. All results were adjusted for age, sex and

educational level. Six individual studies , three systematic review articles and one meta-analysis were examined from Canada, USA, Germany and Australia.

A population based study on the elderly living in Bavaria Germany found that there is a strong relationship between physical activity and the development of incident cognitive function. In this study residents over the age of 55 were enrolled and assessed at baseline and again in 2 years for their level of physical activity and cognitive function. Results showed participants with no physical activity more often developed new cognitive impairment compared to those with moderate or high activity over time even when results were adjusted for depression, chronic disease and cardiovascular risk factors (Etgen et al., 2010).

A Canadian study of older adults explored the relationship between physical activity and cognitive impairment over a 5 year period. It found that older adults who were physically active had a lower risk of cognitive impairment compared with those who were not physically active. There was a significantly lower risk for those with a higher level of physical activity showing a protective effect of regular physical activity on the risk of cognitive impairment and decline, even more so in women. This study showed a dose response effect with less risk of cognitive decline in those with higher levels of physical activity (Laurin, Verreault, Lindsay, Macpherson, & Rockwood, 2001).

Another Canadian study researched walking and its relationship on cognitive function on older Canadian woman. This study assessed the participants at baseline for cognitive function. They assessed physical activity levels by how many city blocks (160m) were walked per week and how many kilocalories were expended per week. Participants were assessed again in 6 to 8 years. This study found that woman who walked more at baseline were less likely to develop cognitive decline, 17% of women who walked the highest number of blocks compared to the

24% who walked the fewest number of blocks developed a three point decline in their MMSE (Yaffe et al., 2001).

A second study on older women from the USA examined the relationship between long term regular physical activity and cognitive functioning. Cognitive assessments in this study were done at baseline and again in two years. Physical activity was assessed at the equivalent or greater than walking at an easy pace. Researchers found that there was less cognitive decline in woman who performed regular physical activity, including easy walking, than those who were less active. A significant association was found between cognitive performance and greater energy expenditures. Regular physical activity was associated with less cognitive decline, especially at higher levels of energy expenditures of at least 1.5 hours a week at the pace of at least easy walking, 21-30 minute/mile. This study did not look how often participants performed physical activity but how many minutes each week were spent on physical activity (Weuve et al., 2004).

Another American prospective study on adults over the age of 65 year examined physical activity that was planned, structured and repeated with the goal of improved health. Cognition was tested at baseline and again approx two years later. This was a self report study and did not look at day to day physical functioning such as household chores. Reported results showed that higher levels of exercise were associated with the absence of substantial cognitive decline after two years even after the results were adjusted for chronic disease (Lytle, Vander Bilt, Pandav, Dodge & Ganguli, 2004).

In a differently focused study, a randomized controlled trail was conducted on older adults in Australia with subjective memory impairment. Participants either took part in a 24 week home based physical activity program or were given education on physical activity and left

to their usual routines. They found that, over 18 months adults, with a subjective memory impairment showed a modest improvement in cognition when they took part in a six month program of physical activity. The physical activity intervention in this study was to have participants perform at least 150 minutes of moderate intensity physical activity per week in three 50 minute sessions. Activity recommended was usually walking but could include strength training or other aerobic exercises (Lautenschlager et al., 2008).

Review articles on the relationship between physical activity and cognitive functioning were examined, three systematic reviews including one from the Cochrane Collection and one meta-analysis. In 2008 the Cochrane Collaboration published a review of aerobic physical activity on the improvement of cognitive functioning in older adults. The assumption was that aerobic fitness benefits cognitive function (Angevaren, Aufdemkampe, Verhaar, Aleman, & Vanhees, 2008). Included in this review were participants who were 55 years and older, not cognitively impaired, included a physical activity intervention and had an outcome measure of cognitive function such as a Mini Mental Status Examination. Eleven studies were included in the final review. Eight of the eleven studies reported that aerobic exercise resulted in improved cardio respiratory function and improvements in short term cognitive speed and visual and auditory attention. That said, the Cochrane Collaboration authors found that the studies failed to have comparable results. It is possible that engagement in physical activity contributes to improvements in cognition driven by psychological and physiological effects other than aerobic fitness. Recommendations were for further research directed on long term intervention trials.

Hamer and Chida (2008) conducted a systematic review on the association between physical activity and the risk of neurodegenerative disease. The studies reviewed were between 1990-2007 and included neurodegenerative disease, dementia and cognition. The final 16 studies

included were ones which had measures of physical activity at baseline, non-demented adults at baseline and a diagnosis of dementia or cognitive impairment at follow up. Findings suggest that physical activity can reduce the risk of dementia and Alzheimer's. Studies did not clearly articulate the optimal dose of physical activity needed to provide protection against dementia and Alzheimer's disease.

Littbrand, Stenvall and Rosendahl (2011) completed a systematic review on the effects of physical exercise on cognitive functions and activities of daily living among people with dementia. Participants in the studies had to have a diagnosis of dementia; ten randomized control trials met this inclusion criteria and data was extracted from them. Physical exercise was compared to usual care and between group analysis was reported. Eight of the ten studies were completed in residential care facilities and the other two in independent housing. The mean age of the participants were 74-85 years. This review found some evidence of the positive effects of physical exercise on overall activities of daily living (ADL). Walking exercise performed individually over 16 weeks and weight bearing exercises over 12 months showed a reduction in ADL decline and prevented a decline in walking performance. Short durations of exercise (two weeks) did not show effects on mobility and exercising less than six weeks did not have any effect on cognitive function. Two studies found that if the exercises were task specific then functional ability with motor skills could be improved. Effects of exercise over time were not reported in most of the studies. One study stated that the effect was not sustained after three months, suggesting that continuous training would be needed with this group of people. The included studies did not provide detailed descriptions of the exercise programs used.

Kramer and Erickson (2007) examined three meta-analytic reviews on the influence of physical activity on cognition. Each review examined the relationship between brain health,

cognition and physical activity. The results showed that personal and environmental factors play a role in how active a person is able to be, such as the person's current environment being conducive to engaging in physical activity as well as lifestyle choices like education. The type of physical activity performed, the length of time it is performed, and the intensity of the performance influenced outcome. These studies showed that the optimal benefits to cognition come from aerobic activity of moderate intensity at least three times a week. An area where further research is still needed is, more detailed information about the ideal physical activity dose to optimize fitness and health benefits for promoting cognitive health with aging

From the available studies, physical activity appears to have a protective role in cognitive functioning of the older adult. There appears to be higher protection if there is an increased level of physical activity at mid and later life for a positive effect on cognition. There are suggestions that there should be a dose recommended for maintenance of cognitive function but an actual dose is not documented or reported in the literature. Until there is solid evidence that a certain type or amount of exercise prevents cognitive decline the current literature provides enough evidence to encourage all older adults take part in regular physical activity.

2.4 Physical activity level recommendations

Several international studies have shown that regular physical activity can lead to a delay in the development of dementia in healthy adults as well as a reduction in the cognitive decline in older adults with a diagnosis of early dementia. There are national and international recommendations on the general requirements of physical activity all adults should take part in. There are some international and Canadian general recommendations on the dose of activity needed for the older adult to maintain function or independence.

The World Health Organization's 2010 global recommendations on physical activity for health state that adults over the age of 65 years should do at least 150 minutes of moderate physical activity per week or at least 75 minutes of vigorous aerobic activity per week of at least 10 minutes in duration at a time. Cardio-respiratory activity should be moderate to vigorous and can be accomplished by brisk or fast walking. The older adult should perform balance activities three times a week and muscle strengthening involving major muscle groups at least two days a week. Older adults respond to strength training well, with regular exercise in this area leading to improvements in mobilization. Strength training can be done as resistance training performing light to moderate movements for six- fifteen repetitions. Progress should be made slowly using varied but specific exercises. Adequate recovery time must be incorporated into an exercise program.

For the prevention of falls and safe mobility, the older adult should include daily balance and mobility tasks that simulate everyday activities such as carrying loads of different weights and balancing with eyes closed. If range of motion is compromised, then stretching activities are very valuable in increasing range of motion. These recommendations aim to improve cardio-respiratory and muscular fitness, functional abilities, bone strength as well as reduce the risk of depression and cognitive decline. Muscle power is extremely important in day to day functioning of older adults; activities such as climbing stairs and rising from a chair require muscle power. Muscle power and strength decrease as people age, which can lead to a daily functioning dependency. In order to maintain and build both muscle strength and power, explosive resistance training with moderate to heavy loads is recommended as an effective exercise with older adults to help maintain functional ability and independence.

Health Canada also recommends that older adults be active every day. For the general adult population Health Canada recommends 30-60 minutes a day of moderate physical activity. Activity can be spread out throughout the day but should be for at least ten minutes at a time (Colley et al., 2011). Moderate activity includes cardio-respiratory fitness activities such as walking, swimming, dancing and cycling. These types of activities should be done four-seven times per week. Flexibility activities should be done daily as they will assist with activities of daily living such as reaching. Flexibility exercise can be done in a formal class or as an informal home activity. Formal flexibility exercises can be yoga or T'ai Chi and informal activities can be activities such as stretching, yard work, gardening and washing floors. Strength and balance exercise challenges muscles and helps to keep muscles and bone strong. These activities should be done two-four times a week and can be informal weight lifting and balance classes or can be in home activities such as carrying groceries or laundry, sitting and standing several times in a row or climbing stairs. Health Canada provides a Physical Activity Guide (2010) to older adults that recommend that activity is incorporated into their daily lives, including activities that provide endurance, flexibility, strength, and balance. This easily available guide provides instructions to the older adult to follow, examples of physical activity and a chart to document progress.

The American Heart Association and the American College of Sports Medicine's recommendations for physical activity in older adults are similar to Health Canada's recommendations. They recommend 30 minutes of moderate aerobic activity on five days each week or vigorous activity a minimum of 20 minutes three days each week. There is more of a focus on the moderate activity than vigorous activity, as vigorous activity has a higher risk of injury and lower adherence. Muscle strengthening is recommended a minimum of two days a

week and recommended that eight-ten exercises be performed on two or more consecutive days using the major muscle groups. Flexibility should be performed two days a week for at least ten minutes at a time. These guidelines recommend that older adults have an approved physical activity plan by a health care provider that integrates both prevention and treatment. Any new activities should be started gradually using a stepwise approach to minimize overuse injury (Nelson et al., 2007).

2.5 Physical activity programs for people with dementia

In Canada and internationally there are physical activities recommendations and programs available for all older adults but when a person is diagnosed with dementia adjusted recommendations may be needed. Physical activity programs commonly available for people with dementia often involve sitting exercises, functional weight bearing, dance or music therapy, and walking. Sitting physical activity exercise programs target gross and fine motor skills and movement and are usually led by trained therapists (Holliman, Orgassa & Forney, 2001). Exercises or dance therapy that have specific one step verbal instructions and continuous visual demonstration to age appropriate music have been shown to improve cognition somewhat in patients with moderate to severe dementia. Exercise to music is thought to motivate people to be more present and alert (Van de Winckel, Feys, Weerdt & Dom, 2004). Functional weight bearing programs are aimed at improving strength, balance and mobility in older adults. These exercises are easy to follow and can be done at home or in small groups. Functional weight bearing training includes everyday tasks such as climbing stairs or rising from a chair. These exercises are performed at as high an intensity as possible in order to improve lower limb strength and balance (Littbrand et al., 2006). Walking programs are easily available to the older adult living in a private residence or to those who have no access to other forms of planned

physical activity. Available studies suggest that older adults who walk regularly and walk quickly have a reduced risk of cognitive decline (Abbott et al., 2004).

In the early stages of dementia people may withdraw from activities they previously took part in. It is essential to help the person remain active. Activity for those with dementia should keep the person's skills and abilities in mind and focus on enjoyment. Activities should be planned as part of the daily routine. As the disease progresses, more repetitive activities should be introduced (Alzheimer's Association, 2012).

2.6 Experiences of Physical Activity in People with Dementia

The significance of physical activity and what physical activity means as it is experienced by people with dementia is not well understood. Available studies in this area describe physical activity as part of the meaningful activities of everyday life. One study described people with dementia as continuing to engage in physical activity, such as long walks; it also noted that family members often notice that involvement in these activities is limited after the onset of dementia and that some activities fall away completely (Phinney, Chaudhury & O'Connor, 2007). People with dementia do not necessarily feel they have a decline in activity level; they often feel that they are doing the same activities they were doing before their diagnosis. People with dementia tend to have a strong desire to continue with their previous way of life as much as possible while coping with the changes that are occurring as their dementia progresses. They try to adapt to their changing situations in ways that are meaningful to them. Physical activities that were taken for granted before the dementia start to become important and are modified in order to maintain continuity in their lives (Menne, Kinney & Morhardt, 2002). The activities that people continue to be involved in are those that have familiarity and give them pleasure and

enjoyment, this showing that peoples preferences for activity do not change with the onset of dementia (Phinney et al., 2007).

Individuals caring for people with dementia need to be aware of previous activities that were meaningful to the person so that these activities can be planned into daily routines. (Menne et al., 2002). It is important for family or caregivers to offer activities that are pleasurable. Keeping physical activities simple and calm is also important because too varied or too stimulating an activity could cause reactions of frustration or agitation (Hasselkus, 1992). Family members or caregivers are in a position to be able to reduce the demands of the person being involved in an activity so that the person with dementia can engage in the activity smoothly and successfully. Families can provide guidance and offer instructions to stay on track and involved in the activity, accompany the person to a physical activity program or be involved in the exercise with them. Most families describe that staying active is important to the quality life of the person with dementia (Phinney, 2006).

With aging, physical limitations are known to affect activities of daily living and mobility, which can influence an older adults' independence. The health benefits of regular physical activity in the older adult are well researched. Several international studies have shown that those adults who have regular physical activity can have a delay in the development of dementia as well as a reduction in the cognitive decline in older adults with a diagnosis of early dementia more than those people who are more sedentary. Current research provides enough evidence to encourage all older adults take part in regular physical activity.

There are national and international recommendations on the general requirements of the kind of physical activity that all adults should take part in. However, are they important to or have meaning for the older adult with dementia?? What are the experiences of older adults with

dementia with physical activity such as gardening, taking walks, occupational and volunteer work, dancing, and doing housework? What are the experiences of physical activity for people with dementia? Many older adults experience barriers to exercise that range from unpleasant sensations and safety to lack of time and lack of support; are older adults with dementia experiencing these same barriers? The significance of physical activity and what physical activity means as it is experienced by people with dementia is not well understood; therefore this is an important area to explore so that we can develop new insights that can eventually guide practice in the area of activity and the older adult with dementia.

3 Research Design and Methodology

3.1 Research Question

What does involvement in physical activity mean for people with dementia?

3.2 Context and Setting

This study is a secondary analysis of data drawn from a larger qualitative investigation on the everyday lives of people living with early dementia. The original study was conducted in two phases: Phase I included ten participants recently diagnosed at a memory clinic (range one-four months post diagnosis), while Phase II included 20 participants living in the community who had been diagnosed with dementia for longer (range one-eight years). Using adapted ethnographic methods (e.g. conversational or "walk along" interviews and participant observation), data was gathered on multiple occasions over a six month to two year period, focusing on obtaining an in-depth understanding of the person's activity in its everyday context. The study questions were: How do people with dementia perceive their involvement in activity and what does it mean to them? What are the social and environmental factors? What effect is there on well-being, autonomy, and identity? Data was collected primarily from participants with dementia, but also included interviews with family and community members. Data for analysis included transcriptions of the recorded interviews, field notes describing each visit, and some video recording and photographs. All participants provided their own informed consent for the original study. All identifying details such as names, towns and streets were changed to protect anonymity.

The original study was based on a theoretical foundation of interpretive phenomenology with the design being informed by ethnographic principles. For this secondary analysis interpretive description will provide the methodological foundation. The research derived from this study, using interpretive description, will be a logical conceptual description using thematic patterns and commonalities that will characterize the meaning of physical activity in people with dementia but will also account for individual variations within them. I chose this method because interpretive description has application potential, and it is the hope that nursing will find sense in these findings and that the findings will provide a background for future assessment, planning and interventional strategies, in keeping with recognized nursing standards of evidence (Thorne, 2004). For the purpose of this study, only interviews that included the person with dementia were analyzed and only those participants who spontaneously talked about physical activity were selected.

3.3. Sample

Purposeful sampling was used for this secondary analysis; participants were selected because their interviews from the original study had some discussion on the subject of physical activity. The final sample was comprised of 12 participants between the ages of 65 and 86 years, six female and six male. The participants represented a range of impairment, and some degree of socio-cultural diversity. The duration the participants had had a diagnosis of dementia was one month to three years. Six of the participants had been newly diagnosed, for less than one year, and six of the participants had been living with dementia for over one year up to three years. Ten of the participants lived in their own homes and two lived in assisted living. While

participants were not asked specifically about other illnesses, to my knowledge they were a healthy group with no evident restrictions on physical ability.

3.4 Data Analysis

This study used a thematic approach to data analysis. Data analysis began with a careful in-depth read of all the transcripts. Each participant had been interviewed more than once. The mean number of interviews was 3.5 (range two to seven interviews) and the duration was over two months to two years. The interviews that included discussion on physical activity and included the person with dementia were flagged. A total of 26 interviews were separated for further analysis. Questions were used to serve as a guide for further analysis: What daily physical activities are the participants involved in? How is physical activity described?

After the initial read through, all transcripts that included discussions on physical activity were read again and preliminary coding, staying close to the data, was started. Relationships were looked for between and across the codes and these relationships were eventually developed into larger categories. There was a continual process of moving in and out, back and forth from the coded details of the interviews to the larger pattern categories. The larger categories were: unable to be as active; enjoyment with being physically active; activity for health; social connections; and contentedness. The categories were then color coded which enabled visualizing within and across participants. Analysis then moved to the development of themes and subthemes. Direct quotations were taken from the transcriptions for examples of the findings. Findings were connected and compared to what is already known in the literature.

Data was securely managed by storing the transcripts and research notes on a secured flash drive and on a single personal lap top computer. The documents were kept in a coded file and access to the file was with a password. The findings from this study comprise descriptions

of types of physical activity people with dementia took part in and what this activity meant to them.

3.5 Ethical considerations

Formal ethics approval was obtained from the University of British Columbia's ethics committee for the original study, which included the possibility to use data for a secondary analysis

4 Research Findings

In this chapter, I will present the insights on physical activity obtained through analysis and interpretation of data from interviews with older adults who have been diagnosed with dementia. As the analytic process evolved, it became apparent to me that much of what these older adults with dementia were describing, in relation to physical activity, conformed well to the general themes that had been apparent in my earlier review of the literature on older adults in general. This strong similarity seemed an aspect that required acknowledgement before I could make sense of the more subtle and nuanced differences that were also apparent in the data that might help us better understand the specific influence physical activity has in dementia. Thus, I have organized these findings in the following manner. I begin with the attraction that physical activity has for this group of older adults, including the types of physical activity they were involved in, and how being active made them feel. The findings that relate to aging in general are presented first, followed by those that are more specific to dementia. I then go on to present how the participants perceived the changes that have occurred in their physical activity, including perceived barriers to being active, and their feelings about these changes. While some of these changes are likely due to aging in general, I will focus more closely on the changes that are more specific to older adults with dementia. Finally, I conclude with a theme that was prominent throughout all of the accounts. The *power of walking* was a central finding of this research. This research reveals important insights about the significance of physical activity for people with dementia, representing as it does a range of meaningful dimensions associated with quality of life.

4.1 The Attraction of Activity

Being older

Like many older adults, the participants in this study were involved in many different types of physical activity, including walking, organized gym classes, general housework, gardening, and swimming. One participant even had a paper route. Many of the reasons why the participants in this study remained involved in activity are comparable to the motivations of any older adult. The notion of physically active citizenship is evident throughout their interviews. They described that being physically active made them feel generally better. They spoke about how exercising was important to them because it keeps them “healthy” and “fit”. Some talked about wanting to exercise so that they could continue to feel and look young, while others found that being active was an important part of managing physical problems that were already present, such as constipation, weight gain and joint pain. CS(2), a participant who had been recently diagnosed with dementia, talked about the range of benefits she received from her daily two to three hour walk at the local botanical gardens. “I have rheumatoid arthritis and the walking helps keep my joints in better shape and I’m hoping it’s keeping my weight down. And it keeps me, I mean, I’m 77 but most people think I am in my 60’s.” She also found that walking helped reduce her problems with constipation. “I’m always constipated and so my sister suggested that the best way is to walk, go and walk around the neighborhood, and it does work.”

Another of the participants was equally enthusiastic about physical activity. CM, a retired nurse, felt that exercise was extremely important to help her remain fit and active. Like CS(2), she walked regularly and took water aerobic classes three times a week. “It’s in the water and you’re into chest level and you’re running back and forth and doing all this exercise and all this

kind of, it's really good for you." She felt it was especially good for her joints. She explained, "you're exercising your knees and your hips and different things in the water."

Beyond the physical benefits, the most common attraction to being active was the pleasure people experienced through their activity. Often this pleasure came from the social interactions with others who were involved with them in the activity. Those who took an exercise class drew pleasure from the people in the class, their relationship with the instructor, or the social activity they took part in after the class. When the participants in this study had someone join them on their walks or in their exercise class, they seem to walk further or exercise more often because they enjoyed the social side of the activity. When one woman was asked about her very active routine, she explained: "Well I enjoy it too, here out with other people, you know, doing stuff."

While those who walked often did so for the primary purpose of getting from one place to another, along the way they also experienced pleasure when they were able to find solitude. They enjoyed being out on their own. One participant talked about enjoying being out and seeing the changing of seasons, while others spoke of how they appreciated being out in the weather, whether it was raining or the sun was shining. Others talked of walking in parks, along trails where they could enjoy nature, hearing the birds and seeing trees and flowers. The men who walked on their own talked of walking through neighborhoods and enjoying the local scenery.

Having dementia

Although much of what these participants reported in terms of the physical and emotional benefits of physical activity seemed to reflect the kinds of experiences that would be common amongst older adults, there were also hints within their accounts that dementia was influential in some of their decisions and actions around physical activity. For example, several of the

participants referred to how they resorted to physical activity because there was little else they could do. As one participant stated, “I do a lot of exercise and enjoy it and I’ve got nothing else to do with my day”. Another participant resorted to walking because he could not drive and couldn’t identify any alternatives, saying “well, what else you doing ya know?” DM’s husband talked about how his wife, who is unaware of her condition, really didn’t have much to do during the day. “Well there is nothing really. We go through our day to day activity, but I have things I have to do. Work and so forth, which keeps me occupied.” The only alternative was when they would sometimes “go for a little walk around the neighborhood.” He went on to say that maybe getting his wife involved in a day program might provide her with more opportunity for activity, but at the current time she did not have a lot to do.

Even though it was not uncommon for participants to talk about not knowing what to do with their day, if there was an exercise class, a dog to be walked, or a spouse saying "let's go for a walk" this provided a desirable focus to their day. Those who walked described how much they enjoyed their outings; getting out on their own or with others made them feel like they were doing something, and gave them a purpose to their day if they didn’t have any other structured or planned activities. Routine walking provided a reason to get moving; it was something to get up for and look forward to.

4.2 Admitting Change

Being older

Like many older adults, participants in this study described a change in the frequency and level of activity from their younger years, and they had various rationales as to why they were not as active as they had been in their youth. Many of the reasons they identified are common barriers that can be applicable to any older adult and not just those with dementia. For example,

they described being less ambitious and less interested in physical activity. One participant described it as being “not motivated”, while another explained how she was, “finding it hard to set aside certain periods” for activity. One man talked of how he felt that with aging he had less energy than he had in his youth. He stated, “I feel like a clock. I feel like I gotta be wound up again. I need a shot of adrenaline or something”. Participants also talked about physical complaints as reasons for being less active; this included having sore legs, getting easily tired, incontinence, and arthritic pain. For some, these physical complaints meant that they were less able to sustain activity. “I don’t go for a walk as long or as much as I have been doing because it, it bothers me. And then I walk for a while and my legs get tired, then I come back in and sit down or lay down, depending on how I feel”. For others, feelings of physical discomfort prevented them from initiating activity in the first place. “With my arms and legs bothering me, I just don’t push it too far. I figure I might as well go to sleep and forget it.”

Characteristics of communities such as the accessibility and location of parks and trails, poor sidewalk design, concrete roads that were difficult to walk on, and quality of the environment such as poor weather conditions (rain, snow, and cold), played a role in influencing participants’ level of physical activity. One participant used to trail walk but because she does not have a car to drive to a park and walking on concrete physically bothers her, she does not walk as often anymore.

“I go out for walks and I can walk quite a distance but, I notice that when you're walking around concrete it's a different story”... it is hard on your feet... that's why I used to like go out rock *hunting*. Because you're, we were walking on rocks but that's different! (Laughs). We didn't seem to mind it then. But, we enjoyed it. We have a, we have a

wonderful club and we have meetings every month. But ah, I don't get out there anymore because I don't have the car”.

With life changes and aging it was necessary for some participants to relocate to a smaller home or an assisted living community. With these moves they faced a sense of loss, with a loss of their belongings, old lifestyle and activity level. One woman talked of missing being active in her garden because she had recently moved from her own home with a garden to an assisted living facility with no garden. “I do miss that, because you can, I always planted the things I liked. Every time I went downtown I'd always haunt the, the stores down there to see what the, you know them uhm, the stores that had...and lug home a whole bunch of stuff (laughs)”. Another participant gave up on home fitness when she moved from a large home with a gym to a smaller home without one.

With aging there can be a decrease in the level of activity from earlier years, but this change does not necessarily cause upset. Not everyone misses activities of the past as they move into a new level of activity that suits their current lifestyle. Participants in this study described that they were comfortable with their current activity level, and felt what they are doing was, in the words of one participant “just right”. One participant described that he used to be very active in the garden, and while he still does some gardening work, now when he sees something that needs to be done, he states: “I can sit here and look at it and I don't get excited and uh, that's a change. Because I usually couldn't look at something like that. I'd have to get out there and do something with it.” He described how it is now his wife who does a lot of the gardening, and when asked if he is okay with that, he said “Oh I don't get upset”. He described himself as “pretty content” in terms of his amount of daily activity, saying “I could do more if I was

inclined, if I wanted to”, and later adding “[I] feel pretty fortunate that I can do anything I want to do”.

One of the less active female participants described her daily activity as “doing a lot of nothing”, although when pressed, it became clear that because she lived alone, it meant that she was the one who took care of her dog, walked outside to feed her fish in the garden pond and looked after the housework. She did state that she enjoys and is comfortable with her current activity level, and is not interested in doing more.

Having dementia

Many of these participants felt that their memory problems interfered with activities that used to be common for them. Some talked of no longer being able to be active in and coaching sports, to swim on their own, or ride a bicycle. As one man explained: “I got these memory problems, it’s been harder for me to try and remember these things so I’m not as active as I was”. Other activities were no longer available to them because they or their family no longer felt the activity was safe for them to take part in. RW used to enjoy daily bike rides, but he isn’t doing that anymore, in part due to his declining memory he thought. TR was an active gardener and builder in the past, but is no longer active in these areas. He wonders if he is unaware that he is not able to do as much as he once used to, “maybe I’m losing some of my smarts. I don’t realize that I can’t do all of that now”. Overall it seemed that participants felt that many of the activities that had been available in their younger years now put them at risk; they couldn’t remember how to do the activity, or they were no longer able to drive themselves to the activity.

Having dementia meant overcoming barriers in order to remain active, while maintaining safety and decreasing risk. Some participants discussed feeling a little frustrated with the decrease in their level of activity or missing past activities, but they said that they were “coping

with it” and were “focused in other ways now”. They made adjustments to activity routines when declining memory made these previous activities too challenging to continue. “Sometimes you know your mind forces you in different directions so I cope with it as best I can”. Many of the participants changed their activity routine to something that they could easily do either on their own or with a companion. One participant and his wife took on doing a paper route after he was diagnosed with dementia for mental and physical activity. Delivering the newspapers in their neighborhood twice a week was a large focus in this man’s week.

Overall, most of the participants were still attracted to being active, but having dementia meant having to find new ways to achieve this. In some cases, in order to stay active they needed some support from others, while others found new ways to be active in the absence of support. One participant used to do a lot of aerobics in her earlier adult years. She remembers how she “used to be able to go” to a class, but she now does some of her aerobic dance moves at home when she wants to. Increasingly she relies on her husband to help her remain active; when he is able, he comes home from work mid-day and they will walk around the neighborhood.

Those who described declining memory as a challenge in staying active had to eliminate certain activities or make adjustments because of this. MH used a local community centre where he had taken some exercise classes. He found the classes regimented, and talked about how he would often “miss out on things”. He does not go as often anymore, but he still uses the community centre for social events and walks back and forth for exercise when attending these. MS finds it hard to remember things and feels he is not as active in ways he used to be because of memory problems; instead he does activities that he knows he is able to do, like completing errands.

4.3 The power of walking

Physical activity is something people wanted to do, although they found themselves needing to do things differently because they were getting older and because of dementia. With these changes, physical activity in the form of walking started to have an important meaningful effect. Walking allowed them to maintain independence; most people were still walking on their own to some degree. It was normal and people had done it all their lives; it was inviting and easy to do. “If there’s nothing doing I’ll walk down the hill and around” explained one person. Walking was a way to still be out in the world with others. It allowed people to preserve their social connections; it was more enjoyable when they did it with others, and to some degree they were finding that they needed others to go along with them.

This group of older adults with dementia found walking meaningful because it allowed them to get out on their own independently. Some would walk back and forth to “town” for basic errands such as getting groceries. One participant stated “there is no reason to sit on your hands”. Most walked rain or shine, one participant saying “I am not a sit arounder” and another “I like walking. Why? Just it’s something you more or less do. It’s just, you know, you walk all your life.”

Those who had increasing safety concerns related to their dementia had to make adjustments so they could stay active, such as wearing ID bracelets so that they could still walk on their own, knowing that if they became lost they could use the ID bracelet to get help. Two gentlemen wore ID bracelets for safety in this study, and both walked a fair distance around their neighborhoods almost daily.

Many participants were no longer driving, with most having lost their license after being diagnosed with dementia. Because of this they were doing things differently, such as walking

back and forth from social outings. A few of the male participants had started walking for this reason, and found they enjoyed the slower pace. MS took up walking after he was no longer able to drive, and often goes out on his own. He feels fortunate that he lives close to downtown. “I’m 10 minutes ... [so] I’m able to walk back and forth.” Walking was an activity these men had not done in the past, but because they had been required to give up their driver’s license, they were now walking to complete errands or to meet with friends and family.

Walking was meaningful to this group because it provided social outings and enjoyment. One active woman joined a walking group in a mall, which she enjoyed because she got the exercise she wanted and was able to join in conversations with other “mall walkers”. Others talked about meeting a friend or a family member for coffee or lunch, and that they would purposely incorporate a walk into the visit. Throughout the interviews, there was talk of how most participants walked on their own, but really enjoyed it more when they had a companion. Many said that when they walked with a friend or family member they would walk more frequently. When they had someone join them it motivated them to walk further, or faster, than they normally would. For example, MS, a 70 year old retired painter who lives alone explained that he would typically walk twice a day, often to complete errands, but he would go on longer outings and walks when his friend GB was able to join him. “Yeah and I can uh, most of what I need to do I can do by walking downtown and the walking is good for me anyway. And uh on other occasions uh, then GB says ‘Let’s make a day of it, go and do such and such’, you know.” When GB is with MS, they will make their outing and the activity longer.

Walking with others was not only more enjoyable, but in some cases it was only possible for people to maintain this activity when they had the support of family or friends. RW was a gentleman who loved to walk, but was unable to initiate or carry through this activity without

help. For a while he had gone for walks with his wife, but when she developed chronic leg pain and was unable to walk with him anymore, they had to develop a new routine. Now they go for drives, and on the way back RW gets out of the car and walks the last portion of the trip back to their home. “We’ll drive somewhere and then when we get say I guess about two and half mile walk, then I get out and walk back and she brings the car.” He also explained that when his daughter is available for a visit he will walk with her to have coffee. “So what my oldest daughter and I do, she drives the car half way there and we’ll walk to the coffee shop and walk back again.”

4.4 Summary

The findings of this study show that older adults with dementia are attracted to physical activity and perceive numerous physical, emotional and social benefits from their involvement. At the same time, the kinds of activities they do and their level of involvement is changing, partly due to the fact that they are older and also as a result of the dementia. Most of the participants were finding ways to work around these changes. The major finding in this study on physical activity in older adults with dementia was that walking was becoming increasingly meaningful to them. Walking permitted them to take a slower pace in their lives and allowed them to appreciate certain things that were not necessarily as important in their youth or healthier years. Walking allowed them to take time to appreciate the things in their lives that they valued such as nature, friends and family.

Walking allowed participants time to enjoy family and friendships. Some who were less able to be involved in walking on their own relied on family members to help maintain this activity. They talked about how when their family or friend suggested a walk they would happily join in and often walk longer and or more often. A very common attraction to being active was

experiencing pleasure with walking with others; this pleasure usually came from the social interactions with those who were involved in the activity with them.

With changes in lifestyle, home and health, various activities had become unavailable to them because of safety risk, time or access. Walking was an activity that they were able to perform independently without the worry of time. Many could walk right out of their homes whenever they wanted to. It was an activity that was easy to do; they already knew how to do it, and had done it all their lives. Those who walked regularly described how much they enjoyed their activity; getting out on their own or with others made them feel like they were doing something, and gave them a purpose to their day. They had found ways to keep up walking by relying on friends or family and safety devices such as ID bracelets. Walking was a way to be out in the world, and in doing this it contributed to their quality of life.

5 The meaning of activity

5.1 Discussion

The purpose of this study was to learn what involvement in physical activity meant for older adults with dementia. The findings from this study show that older people with dementia continue to be attracted to some form of physical activity, even in the face of aging and dementia-related health changes, and that; overall, walking may be the most important way for people with dementia to stay involved in physical activity. All of the participants in this study did some form of walking for an activity, whether they had always done so, or if they had just started walking as a way to be active. From an objective standpoint, it would appear that walking is a tremendously good activity for older adults with dementia; there is a considerable body of evidence showing that it is good for people's health as it can improve muscle strength (Taylor et al., 2004; Tremblay et al., 2007), sleep, (Dubbert et al., 2002; Taylor et al., 2004.), and energy, as well as help to maintain a healthy weight (Health Canada, 2010). But beyond these objective benefits, this study showed that walking was also important for multiple subjective reasons that were highly significant and inherently intertwined. The participants in this study found walking to be easy and accessible, a normal activity that provided for them the sense that they are doing what they have always done. Also, walking was valued both because it can be done alone, and because it can be done with others. It provided both a sense of independence and a sense of connection with others.

Overall, these findings suggest that the significance of physical activity in dementia is very similar to its significance for older adults in general, especially in relation to the social aspects of physical activity and the enjoyment people experience as a result. While growing

older may involve an inevitable loss of strength, energy and fitness, research suggests that older adults today are finding that they are not too old to find enjoyment and pleasure in regular physical activity, especially walking. Walking is one of the most popular everyday activities that older adults take part in as part of physical activity (Feskanich, Willet & Colditz, 2002), and being involved in physical activity improves overall well being and view of self for older adults (Netz, Wu, Becker & Tenenbaum, 2005). The similarities noted among the participants in this study with respect to how walking was perceived suggests that it may have a meaning common to many older adults with dementia. They seem to experience enjoyment from walking in particular because it offers a positive social environment and provides a sense of accomplishment that enhances their self-confidence and self-esteem which taken together, improves their feeling of satisfaction in their life.

These findings echo those of studies that have shown how the significance of meaningful activity does not necessarily change with a diagnosis of dementia (Phinney et al., 2007). Older adults with dementia have a desire to continue with activities, such as walking, while coping with dementia-related changes, and they adapt to their different situations in ways that are meaningful to them (Menne et al., 2002). However, there is very little in the literature specifically on the relationship between physical activity and quality of life in dementia. Potter, Ellard, Rees, & Thorogood, (2011) completed a systematic review in this area, but found there was not enough evidence to determine if physical activity has an effect on quality of life in this population. Although the current study was limited in scope, the findings suggest that the emotional benefits of physical activity are important for people with dementia, and may contribute to their perceived quality of life. Walking in particular allowed people to compare

their ability favorably to others and be recognized for their ability to be active, as well as to maintain some independence and feel a sense of satisfaction from being active on their own.

Walking may be particularly appealing for people with dementia because it remains easy to do when other activities are becoming more difficult as their dementia progresses. Activities that require planning or sequencing – even those that used to be routine – take longer and become challenging and unfamiliar (Phinney, 2008). Walking is different. Like the older adults in the study by Cousins and Tan (2003), people in my study preferred walking because it was simple and accessible, and did not require the exertion of more formal “exercise”. It was easy to walk to the store to complete an errand or to a local café with a family member for coffee or lunch. As many people talked about, walking can be done almost anywhere. They didn’t have to find a special place to walk (although some did when they went trail walking or mall walking); most just had to step outside their door to walk around their neighborhood where it was familiar and inviting. Walking occurred at different times of the day and year, and people went out “rain or shine”; they took pleasure in being outside to experience the changing seasons and enjoy nature. The variety of opportunities available is one of the things that made walking such a practical and pleasurable activity. Participants didn’t always have to find a partner to walk, so they could go whenever they wanted to. Walking didn’t require any special equipment other than a pair of comfortable shoes, which made it a low-cost way for people to be active.

Not only was walking easy and accessible, but it was valued as something that everyone does. As one participant described, no one needs instruction to walk, and it is something that is done throughout life. Walking is a normal activity enjoyed by everyone. This is consistent with previous research that has emphasised the importance of normalizing activities as much as possible so that people with dementia do what they can to feel or seem normal (Gilliard, Means,

Beattie & Daker-White, 2005). Walking is an activity that has always been normal and enjoyable to most participants in their past.

Walking was an important activity because it provided a sense of independence for people with dementia who were becoming increasingly reliant on others for help with some of their day-to-day activities. Participants in this study described that walking made them “feel good”, especially when they described it as an activity they could do on their own. In this way, being physically active through walking may be a healthy coping mechanism for the changes that older adults with dementia experience.

With older adults, “getting around” in their community is seen as essential to maintaining independence (Cousins & Tan, 2003). The findings of my study suggest that this is true also for people with dementia. The Alzheimer’s Society of the UK (2013) promotes walking as a form of physical activity, and encourages people with dementia to remain independent for as long as possible, even if it puts the person at risk. Even in the early stages of dementia, a person can become disoriented or confused for a period of time, and may set off to go walking on their own only to forget where they were going and why (Alzheimer’s Society of BC, 2013). This fact may cause friends and family worry over whether walking alone can put the person in danger (Alzheimer Scotland, 2009). However, even with the potential risk of wandering and having trouble with wayfinding, the findings of my study reinforce the idea that independence is important to maintaining quality of life and dignity for those with dementia, and that walking is a valuable way to sustain independence.

While walking promotes independence, it also supports social interaction. One of the most prominent values associated with walking and being active in this study was that it allowed people to maintain relationships with family, friends and even pets. This is consistent with

research on the relationship between social and physical activity among older people. Physical activity that relates to one's perception of fulfillment and incorporates valued domains of their life (including social engagement) can improve feelings of life satisfaction and well being for older adults in general (Rejeski & Mihalko, 2001), and those who take part in physical activity with others report higher levels of enjoyment (Mullen et al, 2011). In this study, a few people took part in group activities, including group mall walking and organized exercise classes. These participants varied in their degree of impairment, but all talked of their enjoyment in taking part in this kind of activity because it provided them with a social outing after the activity and gave them friendships with instructors and others in the class. Being with familiar people or with others with dementia can be beneficial in helping to normalise difficulties, preventing feeling alone, and model ways of coping (Preston, Marshall & Bucks, 2007).

Finally, this study contributes to the idea that when physical activity is enjoyable, people are more likely to maintain the activity. These findings give cause to consider that feelings of satisfaction and enjoyment from walking could be motivators for people with dementia to remain active; participants themselves described these benefits as key reasons for them to continue to be active.

Although studies have not been conducted with people with dementia specifically to ask this question, research suggests that enjoyment may be a predictor of physical activity participation, especially for older adults. Good health, fitness, social and emotional benefits are all key motivators to be active (Ruby, Dunn, Perrino, Gillis, & Viel, 2011), and a sense of enjoyment may increase participation in physical activity more for older adults than younger adults (Dacey, Baltzell, & Zaichkowsky, 2008). My study suggests that people with dementia are not different in this regard, and the social aspects of physical activity may be key in

increasing their enjoyment. This is similar to findings from McAuley and colleagues (2005) who found that exercise-related social support and its effect on well-being is of particular importance for older adults.

5.2 Study Limitations

In considering implications of this study, it is important to recognize that the findings were based on a secondary analysis of data taken from a larger qualitative study, and only included participants who talked of taking part in physical activity. The exclusion of those who did not talk of physical activity leaves the question of why they were not involved in some type of physical activity unanswered. Moreover, the original study's focus was on everyday activity of older adults with dementia and although it did include physical activity, it was not specifically on physical activity, and therefore at times information on specific issues was not available. As such, the findings are somewhat limited in scope. Although this study did have both community living older adults who were recently diagnosed with dementia and those who had been living with dementia for over two years, it cannot be claimed that this study is comprehensive of the significance of physical activity in all older adults living with dementia, especially as it did not include those who were living alone or people with more advanced dementia who were in full care. Even in light of these limitations however, it is possible to consider implications of the findings for nursing practice and program development.

5.3 Implications for Nursing Practice

The findings of this study provide support for the argument that people with dementia should not be prevented from taking part in normal activities that other older adults take for granted. Providing activities and normalizing activities can and should include asking what the person wants to do or has enjoyed in the past, and consulting with them on their needs (Gilliard et al., 2005). It has been shown that simple nurse counseling can motivate elderly patients to walk for exercise. Dubbert et al., (2002) found that individualized counseling provided by a nurse can lead to initiation and maintenance of a home-based walking program in more elderly patients willing and physically able to undertake such a program. It was also found that participants who had a walking companion had the best adherence to walking. For older adults with dementia, nurses would need to include family or friends of the person in the counseling, and the findings of this study suggest that the walking program may be strengthened by encouraging these family or friends to walk with their partner at least some of the time.

It is important that older adults with dementia make activity a daily part of their lives. There are national and international recommendations on the amount of activity all population groups should aim to achieve. Older adults with dementia can use these as a guide or a goal but just as important is for them to find activities that they enjoy and are part of their regular lives.

Nurses can discuss the level of activity that is safe and appropriate with their client and family members, discuss any medical concerns that might be interfering with more regular activity and review any problems that might affect what activities are safe for them. Family members should be encouraged to assist with setting activity goals such as trying to be moderately active for 30 minutes a day on a regular basis as Health Canada recommends (Health Canada 2010) or the World Health's recommendation of 150 minutes of moderate activity a

week (World Health Organization, 2007). Nurses working with older adults with dementia can assess how much physical activity their clients are getting and if they are not active they can explore reasons why they are not. A USA study found that only half of all adults were asked about their activity habits by their healthcare provider (CDC, 2002). Nurses should ask their client and family members what their plan is to be active and congratulate them on their successes; they should promote changes toward more active lifestyles.

Walking has been shown in this study to be a popular physical activity. Nurses can talk to older adults with dementia or their families about the known benefits of walking, such as better physical and mental health, more energy, better balance (Tremblay et al., 2007) weight maintenance, reduction in stress level (Health Canada), and improved sleep (Taylor et al., 2004), although the findings of this study suggest that, for the people with dementia themselves, the more important benefits might be promoting independence, maintaining social connections, and having fun.

Today's families are busier than ever. Often family members have so many commitments that time together is rare, rather than a part of everyday life. Unfortunately, this disconnect can have a significant effect on those with dementia who may feel distanced from their family or friends. This study has identified that families that make time to be active together benefit, as spending time together provides those with dementia emotional ties and makes them feel valued. When discussing physical activity plans with clients and their families, nurses should ask what areas of their lives they value, such as family, friends, nature, music etc. The findings of this study provide further support for the idea that areas of people's lives that hold value should be incorporated into activity wherever possible (Rejeski & Mihalko, 2001). In this study, friends,

family and even pets were highly valued and were part of what being active meant to these adults with dementia.

This study showed that having a partner join the older adult with dementia can make physical activity more pleasurable; they can provide encouragement, provide social interaction, and help them overcome problems with transportation and safety. Nurses should explore their client's support system and ask if there is someone who can regularly accompany the person with dementia on a walk or to an activity. It is important to try to incorporate activity into daily routines such as walking daily after the dishes are clean or after a meal, or if there is already an established routine, to try to continue with this as long as possible. Nurses can suggest that clients or their family members explore community resources where they can join group activities that include physical activity. They can promote community programs that help build social support for physical activity such as mall walking and encourage communities to improve access to places that older adults can be active, such as walking trails, pools and classes at gyms.

5.4 Future Research

More targeted qualitative research is needed to look more in-depth at questions regarding physical activity, and walking in particular. This research should include perspectives of family members and strategies families use to let the person with dementia walk on their own. Another interesting area of research would be an intervention study to examine the impact of a walking group for people with dementia, and possibly one that incorporates areas that are important to people, such as being outside in nature. Not included in this study were those who were not able to walk due to physical limitations. Further research will need to be completed on activities that can be done from sitting that still include enjoyment and social connections with friends or family.

Conclusion

Previous research has shown that mobility is important to the older adult living with dementia; physical activity can improve muscle strength, which can slow functional decline and improve feelings of well being. But as important as physical activity is for physical health, it is just as important for nurses to focus on maintaining or improving quality of life for adults with dementia. This study suggests that quality of life can be a primary outcome when encouraging those with dementia to be active, targeting areas that are valued by people and are relevant to their daily lives. New activity is not necessary; walking is a form of physical activity that people have done all their lives. Nurses can assist older adults with dementia and their families in setting physical activity goals that focus on the older adult's values and beliefs. Emphasizing the emotional benefits and social connections that walking provides may be more effective at increasing levels of physical activity than highlighting traditional benefits in this group of people. Even as dementia progresses into later stages, walking is one physical activity (although not an activity that every person can perform) that has shown to be popular and easy to maintain. Learnings from this study on the meaning of physical activity in persons with dementia can assist in future planning of specific and targeted physical activity programs that will assist in the healthy aging of this group by increasing and maintaining adequate levels of physical activity.

References

- Abbott, R.D., White, L.R., Ross, G.W., Masaki, K.H., Curb, J.D., & Petrovitch, H. (2004). Walking and dementia in physically capable elderly men. *JAMA*, 292,1447–1453. doi:10.1001/jama.292.12.1447.
- Alzheimer's Association. (2012). *Alzheimer's and dementia caregiving centre: Activities*. Retrieved from <http://www.alz.org/care/alzheimers-dementia-activities.asp?gclid=COixsqChobECFQoZQgodwx69jw>
- Alzheimer's society United Kingdom. (2013). *Leading the fight against dementia*. Retrieved from <http://www.alzheimers.org.uk>
- Alzheimer Society. (2010). Rising tide: The impact of dementia on Canadian society. <http://www.alzheimer.ca/en/Get-involved/Raise-your-voice/Rising-Tide>
- Alzheimer Scotland. (2009). When people with dementia walk: Guidance for carers. *Action on Dementia*, Retrieved from <http://www.alzscot.org/downloads/walking.pdf>.
- Angevaren, M., Aufdemkampe, G., Verhaar, H. J., Aleman, A., & Vanhees, L. (2008). Physical activity and enhanced fitness to improve cognitive function in older people without known cognitive impairment. *Cochrane Database Systematic Review*. 3(3). CD 005381. doi: 10.1002/14651858.CD005381.pub3
- Bonsdorff, V. B., Rantanen, T., Leinoned, R., Kujala, U.M., Tormakangas, T., Manty, M. & Heukkinen, E. (2009). Physical activity history and end-of-life hospital and long-term care. *Journal of Gerontology Medical Sciences*, 64, 888-895. doi: 10.1093/gerona/glp029

- Brawley, L.R., Rejeski W.J., & King, A.C. (2003). Promoting physical activity for older adults: the challenges for changing behavior. *American Journal of Preventative Medicine*, 25, 172-183. doi.org/10.1016/S0749-3797(03)00182-X,
- Centers for Disease Control and Prevention. (2002). *Promoting active lifestyles among older adults*. Atlanta: CDC, National Center for Chronic Disease Prevention and Health Promotion. Nutrition and Physical Activity. URL: http://www.cdc.gov/nccdphp/dnpa/physical/recommendations/older_adults.htm
- Colley, R.C., Garriguet, D., Janssen, I., Craig, C.L., Clarke, J. & Tremblay. (2011). Physical activity of Canadian adults: Accelerometer results from the 2007 to 2009 Canadian health measures survey. <http://www.statcan.gc.ca/pub/82-003-x/2011001/article/11396-eng.pdf>
- Cousins, S.O. (1995). Social support for exercise among elderly woman in Canada. *Health Promotion International*, 10(4), 273-282. doi: 10.1093/heapro/10.4.273.
- Cousins, S. O. B., & Tan, M. (2003). Sources of efficacy for walking and climbing stairs among older adults. *Physical & Occupational Therapy in Geriatrics*, 20(3-4), 51-68. doi:10.1080/J148v20n03_04
- Dacey, M., Baltzell, A., & Zaichkowsky, L. (2008). Older adults' intrinsic and extrinsic motivation toward physical activity. *American Journal of Health Behavior*, 32(6), 570-582. doi: 10.5993/AJHB.32.6.2
- De Groot, G. C. & Fagerstrom, L. (2011). Older adults' motivating factors and barriers to exercise to prevent falls. *Scandinavian Journal of Occupational Therapy*, 18 (2), 153-160. doi:10.3109/11038128.2010.487113
- de Vos, N.J., Singh, N.A., Ross, D.A., Stavrinou, T.M., Orr, R., & Fiatarone, M.A. (2005). Optimal load for increasing muscle power during explosive resistance training in older

- adults. *Journal of Gerontology. Series A Biological Science and Medical Science*, 60, 638-647. doi: 10.1093/gerona/60.5.638
- Dubbert, P. M., Cooper, K. M., Kirchner, K. A., Meydrech, E. F., & Bilbrew, D. (2002). Effects of nurse counseling on walking for exercise in elderly primary care patients. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 57(11), 733-740. doi: 10.1093/Gerona/57.11.M733
- Etgen, T., Sander, D., Huntgeburth, U., Poppert, H., Forstl, H., & Bickel, H. (2010). Physical activity and incident cognitive impairment in elderly persons: the INVADE study. *Archives of Internal Medicine*, 170(2), 186-193. doi:10.1001/archinternmed.2009.498.
- Ferri, C. P., Prince, M., Brayne, C., Brodaty, H., Fratiglioni, L., Ganguli, M., ... & Sczufca, M. (2006). Global prevalence of dementia: a Delphi consensus study. *The Lancet*, 366(9503), 2112-2117. doi.org/10.1016/S0140-6736(05)67889-0,
- Feskanich, D., Willett, W., & Colditz, G. (2002). Walking and leisure-time activity and risk of hip fracture in postmenopausal women. *JAMA: the Journal of the American Medical Association*, 288(18), 2300-2306. doi:10.1001/jama.288.18.2300.
- Forbes, D., Forbes, S., Morgan, D.G., Markle-Reid, M., Wood, J., & Culum, I. (2008). Physical activity program for persons with dementia. *Cochrane Database Systematic Reviews*, 3. doi: 10.1002/14651858.CD006489.pub2
- Gilliard, J., Means, R., Beattie, A., & Daker-White, G. (2005). Dementia care in England and the social model of disability lessons and issues. *Dementia*, 4(4), 571-586. doi: 10.1177/1471301205058312
- Government of Canada. *Canada's aging population*. 2002. Web. <<http://dsp-psd.pwgsc.gc.ca/Collection/H39-608-2002E.pdf>>.

- Hamer, M., & Chida, Y. (2009). Physical activity and risk of neurodegenerative disease: A systematic review of prospective evidence. *Psychological Medicine*, 39, 3-11.
doi.org/10.1017/S0033291708003681
- Health Canada. (2010). *Physical activity guide for older adults*. Web.
<<http://www.phac-aspc.gc.ca/hp-ps/hl-mvs/pa-ap/index-eng.php>>.
- Holliman, D. C., Orgassa, U. C., & Forney, J. P. (2001). Developing an interactive physical activity group in a geriatric psychiatry facility. *Activities, Adaptation & Aging*, 26(1), 57-69. doi: 10.1300/J016v26n01_04
- Kramer, A.F. & Erickson, K.I. (2007). Effects of physical activity on cognition, well-being, and brain: Human interventions. *Alzheimer's & Dementia*, 3, 45–51.
doi.org/10.1016/j.jalz.2007.01.008
- Laurin, D., Verreault, R., Lindsay, J., Macpherson, K. & Rockwood, K. (2001). Physical activity and risk of cognitive impairment and dementia in elderly persons. *Archives of Neurology*, 58, 498–504. doi:10.1001/archneur.58.3.498.
- Lautenschlager, N. T., Cox, K. L., Flicker, L., Foster, J. K., van Bockxmeer, F. M., Xiao, J., ... & Almeida, O. P. (2008). Effect of physical activity on cognitive function in older adults at risk for Alzheimer disease. *JAMA: the Journal of the American Medical Association*, 300(9), 1027-1037. doi:10.1001/jama.300.9.1027.
- Littbrand, H., Rosendahl, E., Lindelof, N., Lundin-Olsson, L., Gustafson, Y. & Nyberg, L. (2006). A high-intensity functional weight-bearing exercise program for older people dependent in activities of daily living and living in residential care facilities: evaluation of the applicability with focus on cognitive function. *Physical Therapy*, 86(4), 489–98.

- Littbrand, H., Stenvall, M. & Rosendahl, E. (2011). Applicability and effects of physical exercise on physical and cognitive functions and activities of daily living among people with dementia. A systematic review. *American Journal of Physical Medicine and Rehabilitation*, 90 (6), 495-518. doi : 10.1097/PHM.0b013e318214de26
- Litt, M.D., Kleppinger, A., & Judge, J.O. (2002). Initiation and maintenance of exercise behavior in older woman: predictors from the social learning model. *Journal of Behavior Medicine*, 25(1), 83-97.
- Luukinen, H., Lehtola, S., Jokelainen, J., Vaananen-Sainio, R., & Lotvonen, S. (2006). Prevention of disability by physical activity among the elderly: a population-based, randomized, controlled trial. *Scandinavian Journal of Primary Health*, 24, 199-205. doi:10.1080/02813430600958476
- Lytle, M.E., Vander Bilt, J., Pandav, R.S., Dodge, H.H. & Ganguli, M. (2004). Exercise level and cognitive decline: The MoVIES Project. *Alzheimer's Disease and Associated Disorders*,18(2), 57-64.
- McAuley, E., Elavsky, S., Jerome, G. J., Konopack, J. F., & Marquez, D. X. (2005). Physical activity-related well-being in older adults: social cognitive influences. *Psychology and Aging*, 20(2), 295. doi: 10.1037/0882-7974.20.2.295
- Menne, H. L., Kinney, J. M., & Morhardt, D. J. (2002). 'Trying to continue to do as much as they can do'. Theoretical insights regarding continuity and meaning making in the face of dementia. *Dementia*, 1(3), 367-382. doi: 10.1177/147130120200100308
- Miller, C. A. (2011). *Nursing for wellness in older adults*. (6th ed.). (pp. 259-285) Philadelphia: Lippincott, Williams & Wilkins.

- Mullen, S. P., Olson, E. A., Phillips, S. M., Szabo, A. N., Wójcicki, T. R., Mailey, E. L., ... & McAuley, E. (2011). Measuring enjoyment of physical activity in older adults: invariance of the physical activity enjoyment scale (paces) across groups and time. *International Journal of Behavioral Nutrition and Physical Activity*, 8(1), 1-9. doi: 10.1186/1479-5868-8-103
- Netz, Y., Wu, M., Becker, B. J., & Tenenbaum, G. (2005). Physical activity and psychological well-being in advanced age: a meta-analysis of intervention studies. *Psychology and Aging*, 20(2), 272. doi: 10.1037/0882-7974.20.2.272
- Nied, R.J., & Franklin, B. (2002). Promoting and prescribing exercise for the elderly. *American Family Physician*, 65(3), 419-426.
- Nelson, M. E., Rejeski, W. J., Blair, S. N., Duncan, P. W., Judge, J. O., King, A. C., ... & Castaneda-Sceppa, C. (2007). Physical activity and public health in older adults: Recommendation from the American College of Sports Medicine and the American Heart Association. *Medicine and science in sports and exercise*, 39(8), 1435.
- Paterson, D.H., Jones, G.R. & Rice, C.L. (2007). Ageing and physical activity: evidence to develop exercise recommendations for older adults. *Applied Physical, Nutrition and Metabolism*, 32 (2), 69-108. doi: 10.1139/H07-111
- Phinney, A. (2006). Family strategies for supporting involvement in meaningful activity by persons with dementia. *Journal of Family Nursing*, 12(1), 80-101.
doi: 10.1177/1074840705285382
- Phinney, A., Chaudhury, H. & O'Connor, D.L. (2007). Doing as much as I can do: The meaning of activity for people with dementia. *Aging and Mental Health*, 11(4), 384-393.
doi: 10.1080/13607860601086470

- Phinney, A. (2008). Toward understanding subjective experiences of dementia. In M. Downs & B. Bowers (Eds.), *Excellence in dementia care: Research into practice* (pp. 35-45). Berkshire, England: Open University Press.
- Potter, R., Ellard, D., Rees, K., & Thorogood, M. (2011). A systematic review of the effects of physical activity on physical functioning, quality of life and depression in older people with dementia. *International Journal of Geriatric Psychiatry*, 26(10), 1000-1011. doi: 10.1002/gps.2641
- Preston, L., Marshall, A., & Bucks, R. S. (2007). Investigating the ways that older people cope with dementia: A qualitative study. *Aging & Mental Health*, 11(2), 131-143. doi: 10.1080/13607860600844572
- Prohaska, T.R., Eisenstein, A.R., Satariano, W.A., Hunter, R., Bayles, C.M., Kurtovich, E., ...Ivey, S.L. (2009). Walking and the preservation of cognitive function in older populations. *The Gerontologist*, 49, 86-93. doi: 10.1093/geront/gnp079.
- Public Health Agency of Canada. *Health Canada physical activity guide for older adults*. 2010. Web. <<http://www.phac-aspc.gc.ca/hp-ps/hl-mvs/pa-ap/index-eng.php>>.
- Rejeski, W. J., & Mihalko, S. L. (2001). Physical activity and quality of life in older adults. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 56(2), 23-35. doi: 10.1093/gerona/56.suppl_2.23
- Resnick, B., Orwig, D., Magaziner, J., & Wynne, C. (2002). The effect of social support in exercise behavior in older adults, *Clinical Nursing Research*, 52-70. doi: 10.1177/105477380201100105

- Ritchey, L. H., Ritchey, L. H., & Dietz, B. E. (2001). Clarifying the measurement of activity. *Activities, Adaptation & Aging*, 26(1), 1-21. doi: 10.1300/J016v26n01_01
- Ruby, M.B., Dunn, E.W., Perrino, A., Gillis, R. & Viel, S. (2011). The invisible benefits of exercise. *Health Psychology*, 30(1), 67-74. doi: 10.1037/a0021859.
- Schutzer, K.A. & Graves, B.S. (2004). Barriers and motivations to exercise in older adults. *Preventative Medicine*, 39 (5), 1056-1061. doi: 10.1016/j.ypmed.2004.04.003.
- Taylor, A. H., Cable, N. T., Faulkner, G., Hillsdon, M., Narici, M., & Van Der Bij, A. K. (2004). Physical activity and older adults: A review of health benefits and the effectiveness of interventions. *Journal of Sports Sciences*, 22(8), 703-725.
doi: 10.1080/02640410410001712421
- Thorne, S. , Kirkham, S.R. & Macdonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing and Health*, 20, 169-177
- Thorne, S., Kirkham, S.R. & O'Flynn-Magee. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3 (1)
- Tinetti, M.E. (2003). Preventing falls in the elderly persons. *New England Journal of Medicine*, 348, 42-49. doi: 10.1056/NEJMcp020719
- Van de Winckel, A., Feys, H., De Weerd, W. & Dom, R. (2004). Cognitive and behavioural effects of music-based exercises in patients with dementia. *Clinical Rehabilitation*, 18(3), 253–60. doi: 10.1191/0269215504cr750oa
- Weuve, J., Kang, J.H., Manson, J.E., Breteler, M.M.B., Ware, J.H., Grodstein, F. (2004). Physical activity, including walking, and cognitive function in older women. *JAMA*, 292(12), 1454–61. doi:10.1001/jama.292.12.1454.

World Health Organization. (2007). *Guide for population based approaches to increasing levels of physical activity*. Geneva. Web.

<http://www.who.int/dietphysicalactivity/PA-promotionguide-2007.pdf> Geneva

Appendix

Description of Participants

MS, a 70 year old male who is an artist/painter and retired salesman. MS had the support of a female friend but lives alone in a first floor apartment.

SP, an 86 year old widowed woman who was a record purchaser and painter. She lives in an assisted living apartment on the third floor and has support from her son.

RW, a 74 year old retired father and husband. He is married to second wife; who is still working and they live in a townhouse complex. He used to coach his kids sports teams and now supports his children coaching sports to their children, he involved in their activities

TR, an 81 year old male, retired builder. He is married with six children and eleven grandchildren. He and his wife live in a rancher home

CM, a 66 year married mother of five. She is a retired nurse who lives in ranch-style home. She is in the early stages of dementia.

LR, an 84 year old widow, retired department store clerk. He has a friend and neighbor as her main support. She leads a very solitary life and spends a lot of her time with her Jack Russell Terrier dog.

MH, an 84 year old married man. He is a retired accountant, father and an artist-painter in the past.. He and his wife live in a semi-detached town home.

DP, is a gentleman who was involved in accident that required brain surgery 9 years ago. A psychiatrist diagnosed DP with dementia 1.5 years ago and attributes the memory lost to the brain injury. DP is married and lives in a large detached house in a cul-de-sac.

CS(1), was diagnosed with dementia 2.5-3 years ago. She lives alone in assisted living. She has support from her daughter but described herself as a person who doesn't really have any friends and prefers her own company.

EB, an 81 year old man who lives in own house with his wife. EB is active with a personnel trainer.

CS(2), was recently diagnosed with Alzheimer's (2009). She lives alone in one story house, never been married and has no children. She has support from a sister.

DM, is married and lives in her own home with her husband. She is completely unaware of her condition. DM was a very successful travel agent and pharmaceutical rep.