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Health Literacy of Individuals Living with Parkinson's Disease

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Graduate Program in Nursing

A thesis submitted in partial fulfillment of the requirements for the degree in Master of Science

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HEALTH LITERACY OF INDIVIDUALS LIVING WITH PARKINSON'S DISEASE

(Thesis format: Integrated Article)

by

Nicole LeBlanc

Graduate Program in Nursing

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Science in Nursing

The School of Graduate and Postdoctoral Studies
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London, Ontario, Canada

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Abstract

In the past two decades, there has been an increased interest in the development of self-management programs for people with chronic diseases. Fundamental to chronic disease management is adequate literacy and health literacy skills. Research on the health literacy skills of individuals managing Parkinson's disease (PD) is seemingly absent from the research literature. The purpose of this study was to assess the health literacy skills of older adults managing PD and to examine the relationships of functional health literacy, self-efficacy, social support, and empowerment in this population. Using a cross-sectional design, this study surveyed 33 older adults living with PD within southwestern Ontario. Functional health literacy was positively correlated with self-efficacy ($r=.13$) and empowerment ($r=.20$) in individuals living with PD. As well, there was an association between functional health literacy and social support. Findings suggest that self-efficacy, social support, and empowerment may affect PD patients' ability to find, read, understand, and communicate health-related information.

Keywords: Parkinson's disease, functional health literacy, self-efficacy, empowerment, social support

Dedication

I would like to dedicate my thesis to my mother, father, brother, and Glen. I would not have made it this far without your ongoing guidance, love, and support.

Acknowledgments

I would like to acknowledge my supervisor, Dr. Lorie Donelle, for her ongoing guidance and support. I would also like to acknowledge my thesis committee members, Dr. Yolanda Babenko-Mould and Dr. Carol Wong, for their ongoing assistance with my thesis work.

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Chapter One

Introduction

In Canada, more than 100,000 individuals are diagnosed with Parkinson's disease (PD) (Parkinson Society Canada [PSC], 2011). Parkinson's disease is a chronic neurodegenerative disorder that is caused by a loss of dopamine-producing cells in the brain (Calne, 1993; PSC, 2011). It can have a significant impact on the physical, mental, and social well-being of an individual. The symptoms of PD vary depending on the individual, however the most common physical expression of the disease is muscle tremor (Calne, 1993; National Institute of Neurological Disorders and Stroke [NINDS], 2013; PSC, 2011). Muscle tremor often begins on one side of the body, mainly affecting the hand; however, as the disease progresses it may affect both sides of the body. Individuals with PD may also experience slowed and rigid movement, impaired balance, and tightening of the muscles (American Parkinson Disease Association, 2013; Calne, 1993; PSC, 2011). As the disease progresses, individuals may also experience fatigue, difficulty speaking and writing, cognitive deficit changes, difficulty swallowing, and sleep disturbances (American Parkinson Disease Association, 2013; Calne, 1993; PSC, 2011). With no known cure, treatment of PD is directed at symptom management and the development of strategies to cope with the physical, emotional, and cognitive changes associated with this progressive disease. Despite improvements in the treatment of PD, most individuals rely on various medications and surgical procedures to alleviate their symptoms.

Males are more commonly diagnosed with PD than females, with a male to female ratio of three to two (PSC, 2011). Parkinson's disease can affect a wide range of individuals and although it is most commonly diagnosed among individuals 50 to 60

years of age (late onset), the prevalence rate in individuals younger than 40 years of age (early onset) is rising (5-10% of all cases) (American Academy of Neurology, 2013; PSC, 2011). Current estimates indicate that five to ten percent of individuals with PD will develop symptoms before the age of 40 years (PSC, 2011; Schrag, Ben-Shlomo, Brown, Marsden, & Quinn, 1998).

In Canada, three out of five people over the age of 20 years are living with a chronic disease (Public Health Agency of Canada [PHAC], 2013). With the increased prevalence of chronic diseases, Canadians are expected to take on greater accountability for their own health (Health Canada, 2007; Raphael & Curry-Stevens, 2004). In the last two decades, there has been an increased interest in the development of self-management programs for people with chronic diseases (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Rootman & Ronson, 2003). Much of the success in managing a chronic disease is reliant on access to, and understanding of verbal or written information, participation in decision-making, and personal commitment to an established treatment plan. Fundamental to self-care and chronic disease management are adequate literacy and health literacy skills. The relationship between literacy and health outcomes is well-documented in the literature indicating that low literacy is both directly and indirectly related to poor health outcomes (Canadian Council on Learning [CCL], 2007; DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Nutbeam, 2008). Many individuals have difficulty self-managing their chronic disease due to low health literacy skills (Rootman & Ronson, 2003). In a recent discussion paper, Mitic and Rootman (2012) state that 88 percent of seniors (age 65 years and older) are significantly challenged in making health-related decisions on their own as a consequence of limited literacy and health literacy skills. Healthcare professionals should consider this when developing self-management

programs given the relationship between limited health literacy skills and diminished engagement in effective self-management (Mitic & Rootman, 2012).

Literacy and Health Literacy Skill of Canadians

The Canadian Expert Panel on Health Literacy defines health literacy as “[t]he ability to access, understand, evaluate, and communicate information as a way to promote, maintain, and improve health in a variety of settings across the life-course” (Rootman & Gordon-El-Bihbety, 2008, p. 11). Earlier definitions of health literacy focused on *functional skills* such as the ability to manage words (prose / document literacy) and numbers (numeric literacy) within a healthcare context (Ad Hoc Committee on Health Literacy, 1999). Nutbeam’s (2000) definition of health literacy incorporates a broader, more complex and interconnected set of abilities, such as verbal and written communication skills, and reading and acting upon written information for self, community, and societal health improvement. Nutbeam defines health literacy as “the personal, cognitive, and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health” (p. 263) and proposes that health literacy skills are also associated with the concepts of self-efficacy, social support, and empowerment. Current estimates indicate that 42 percent of Canadian adults aged 16 to 65 have limited *literacy* (prose and numeracy) skills (Statistics Canada, 2005). This number increases to 48 percent when individuals aged 66 and older are included (Statistics Canada, 2005).

Moreover, a large percentage of Canadians have limited *health* literacy skills. Individuals with limited (e.g., inadequate and marginal health literacy scores) health literacy skills accessed more hospital emergency services, knew less about their chronic disease condition, were less likely to read written medical information, and were less

likely to seek out written health information than individuals with adequate health literacy skills (Baker et al., 2002; Gazmararian, Williams, Peel, & Baker, 2003; Kalichman, Benotsch, Suarez, Catz, & Miller, 2000; Koo, Krass, & Aslani, 2007). Individuals who have low health literacy skills are most often older adults, of Aboriginal heritage, recent immigrants, people with lower levels of education, and those with limited financial resources (Mitic & Rootman, 2012; Nielsen-Bohlman, Panzer, Hamlin, & Kindig, 2004).

Recent statistics have shown that 60 percent of adults and 88 percent of seniors in Canada do not have adequate health literacy skills (PHAC, 2013). Individuals over the age of 65 have difficulty managing their health on their own because of modern health information demands (PHAC, 2013). Healthcare professionals, including nurses, are ideally positioned within the healthcare system to support and integrate health literacy into daily practice. People living with a chronic disease, such as PD, often have a complex care plan involving several medications and medical instructions (PHAC, 2013). By providing clear, reliable information to seniors, healthcare professionals are enabling them to effectively manage their health.

Despite the chronic and complex nature of the disease, the high prevalence of PD among older adults, the expectation for self-care management, and the progressive need for diverse health information and services, there is no published research investigating the health literacy skills among adults managing PD. Knowing that nearly half of Canadian adults have low literacy skills and that low health literacy skills is common (Mitchell & Begoray, 2010), it is critical to understand how the proposed factors that contribute to adequate health literacy such as functional health literacy, self-efficacy, social support, and empowerment are related in individuals with PD (Nutbeam, 2000). Understanding how these factors are related may provide greater insight into the skills

and knowledge needed to develop health literacy skills in support of better health and health-enhancing behaviours (Nutbeam, 2008).

Nutbeam (2000) outlined a framework that describes three broad categories of health literacy: functional, interactive, and critical health literacy. He describes health literacy as both a contributor and an outcome of health promotion actions, particularly health education and communication activities (Nutbeam, 2000). Health literacy is influenced by individual characteristics and behavioural patterns, as well as social, economic, and environmental circumstances (Nutbeam, 2000). In this framework, Nutbeam identifies a relationship between the three categories as indicated by various outcomes at both the individual and community level. For example, he proposed that improved knowledge, which is an indicator of functional health literacy, may enable improved self-efficacy and interaction with social groups (interactive health literacy) and also lead to greater empowerment (critical health literacy) (Nutbeam, 2000).

Nutbeam (2000) describes functional health literacy as the outcome of health education processes that are focused on the transmission of factual information (e.g., health risks, navigating the health system). *Functional* health literacy is reflected in basic reading, writing, and numeric skill for everyday use. Adequate functional health literacy is reflected in the comprehension and communication of health facts, awareness of health services, and use of the health system (Nutbeam, 2000). Examples of this type of health literacy may include reading and understanding a health information brochure or instructions on a pill bottle. Nutbeam describes *interactive* health literacy as the outcome of health education processes that aim to improve an individual's ability to use advanced cognitive and social skills in a social environment. Nutbeam proposed that individuals who have adequate interactive health literacy are more likely to have greater motivation

and confidence in their ability to use information and services to act in ways that enhance health. Lastly, *critical* health literacy is the outcome of cognitive and skills development, particularly skills that are focused on supporting social and political action (Nutbeam, 2000). Critical health literacy can be linked to both individual and population benefit and represents advanced analytical, advocacy, and social skills geared toward critiquing broader social and political structures to create positive change within communities and at the broader societal level (Nutbeam, 2000). For example, individuals with critical health literacy skills have the knowledge, skills, and motivation to participate in collective action (e.g., lobbying) in support of a community or social cause. Empirical research testing of Nutbeam's framework of health literacy is limited within the published research literature. This study examined the relationships of functional health literacy, self-efficacy, social support, and empowerment in individuals managing PD.

Possible indicators of health literacy include: ability to access health information and services, improved health knowledge and compliance with recommended treatment plans (functional health literacy), improved self-confidence and social support (interactive health literacy), and greater empowerment (critical health literacy) (Nutbeam, 2000). Nutbeam (2000) proposed that improved functional health literacy may warrant improved self-efficacy and greater empowerment; however, an understanding of these relationships in individuals with PD is limited.

Empirical testing of Nutbeam's (2000) health literacy framework is limited within the published research literature. However, in 1997, a group of researchers studied self-efficacy in individuals with PD (Fujii et al.). They found that more than half of the participants had low general self-efficacy (Fujii et al., 1997). In a more recent research study, McCabe and O'Connor (2012) found that increased social support was

significantly related to enhanced quality of life in individuals living with PD.

Empowerment has also been identified as an important health-enhancing strategy for individuals managing PD. In 2006, Holloway developed and implemented a care pathway to facilitate more organized care for individuals with PD. Patient and caregiver empowerment was identified as one of the most positive outcomes of the pathway (Holloway, 2006). The findings from these studies are helpful in understanding the importance of self-efficacy, social support, and empowerment in relation to PD; however, the relationships between these variables is poorly understood. As well, research on the health literacy skills of individuals managing PD is not evident within the published research literature.

Significance and Purpose of the Study

The chronic and progressive nature of PD dictates the need for continuous and accurate information and services for individuals managing this disease. However, as previously mentioned, research on the health literacy skills of individuals managing PD is seemingly absent from the research literature. In order to provide accurate information and services for individuals with PD, it is important to have a thorough understanding of their information needs and health literacy skills, as well as have an understanding of how functional health literacy, self-efficacy, social support, and empowerment are related in this population.

This research study will contribute to the healthcare of individuals with PD in multiple ways. First, the knowledge gained from this study could be used in the development of programs and services (e.g., support groups) for individuals with PD. The significance of this study also lies in the opportunity to develop a greater understanding of the relationships of functional health literacy, self-efficacy, social

support, and empowerment in individuals with PD. Findings from this study may assist healthcare professionals in understanding the critical nature of health literacy. As well, the findings from this study will contribute to the growing body of literature on health literacy.

The purpose of this research study was to assess the health literacy skills of older adults managing PD and to examine the relationships of functional health literacy, self-efficacy, social support, and empowerment in individuals living with PD.

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Chapter Two

Introduction

In Canada, more than 100,000 individuals are diagnosed with Parkinson's disease (PD) (Parkinson Society Canada [PSC], 2011). Parkinson's disease is a chronic disorder that is caused by a loss of dopamine-producing cells in the brain (Calne, 1993; PSC, 2011). The most common symptom of PD is muscle tremor; however, the symptoms vary depending on the individual (National Institute of Neurological Disorders and Stroke [NINDS], 2013; PSC, 2011). Other common symptoms include slowed and rigid movement, impaired balance, and tightening of the muscles (American Parkinson Disease Association, 2013; PSC, 2011). As the disease progresses, individuals may also experience fatigue, difficulty speaking and writing, cognitive deficit changes, difficulty swallowing, and sleep disturbances (American Parkinson Disease Association, 2013; PSC, 2011). Management of PD is directed at symptom management and the development of strategies to cope with the many changes associated with the disease.

In Canada, there is an increased prevalence of chronic health conditions such as cardiovascular disease, diabetes, and PD (Public Health Agency of Canada [PHAC], 2013). These conditions tend to be incurable and require management rather than curative regimens of care. As the prevalence of chronic disease rises, Canadians are expected to take on greater accountability for their own health (Health Canada, 2007; Raphael & Curry-Stevens, 2004). Consequently, there has been a substantial increase in the development of self-management programs for individuals living with a chronic disease, including PD (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Rootman & Ronson, 2003). Self-management can be particularly difficult for individuals who have

limited literacy (reading, writing, and numeracy) skills (PHAC, 2013). Fundamental to self-care and chronic disease management are adequate literacy and health literacy skills.

Because health literacy is an evolving concept, it has been defined in various ways. For example, the World Health Organization ([WHO], 1998) defines health literacy as the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health. Another commonly used definition of health literacy is “[t]he ability to access, understand, evaluate, and communicate information as a way to promote, maintain, and improve health in a variety of settings across the life-course” (Rootman & Gordon-El-Bihbety, 2008, p. 11). The concept of health literacy has evolved over the years with earlier definitions focusing on *functional skills* such as the ability to manage words (prose / document literacy) and numbers (numeric literacy) within a healthcare context (Ad Hoc Committee on Health Literacy, 1999). More recent definitions of health literacy incorporate a broader, more complex and interconnected set of abilities, including verbal and written communication skills, as well as reading and acting on written information for self, community, and societal health improvement (Nutbeam, 2000). Current estimates indicate that 60 percent of adults and 88 percent of seniors in Canada do not have adequate health literacy skills (PHAC, 2013). Consequently, seniors are significantly challenged in making health-related decisions on their own (Mitic & Rootman, 2012).

Despite the chronic and complex nature of PD, the high prevalence of the disease among seniors, the rising expectation for self-care management, and the progressive need for diverse health information and services, there is no published research investigating the health literacy skills of adults living with PD. Nutbeam (2000) offers a theoretical

framework for understanding health literacy and possible related factors. Because there is an increased emphasis on the development and use of self-management programs, it is important to identify the health literacy skills of individuals managing PD and how it relates to factors such as self-efficacy, social support, and empowerment.

The purpose of this research study was to assess the health literacy skills of older adults managing PD and to examine the relationships of functional health literacy, self-efficacy, social support, and empowerment in individuals living with PD. Investigating these relationships may provide greater insight into the skills and knowledge needed to develop adequate health literacy skills in support of better health and health-enhancing behaviours (Nutbeam, 2008).

Theoretical Framework

Nutbeam's (2000) framework of health literacy was used as the guiding theoretical framework. Nutbeam outlined a framework that describes three broad categories of health literacy: functional, interactive, and critical health literacy.

Functional health literacy is reflected in basic reading, writing, and numeric skill for everyday use. Adequate functional health literacy is reflected in the comprehension and communication of health facts, awareness of health services, and use of the health system (Nutbeam, 2000). *Interactive* health literacy involves the development of personal (cognitive and social) skills in a supportive environment. Nutbeam (2000) proposed that individuals who have adequate interactive health literacy are more likely to have greater motivation and confidence in their ability to use information and services to act in ways that enhance health. Lastly, *critical* health literacy is the outcome of cognitive and skills development, particularly skills that are focused on supporting social and political action (Nutbeam, 2000). Critical health literacy can be linked to both

individual and population benefit and represents advanced analytical, advocacy, and social skills geared toward critiquing broader social and political structures to create positive change within communities and at the broader societal level (Nutbeam, 2000). Within this framework, relationships exist between the three categories as indicated by various outcomes at both the individual and community level. For example, improved knowledge, which is an indicator of functional health literacy, may enable improved self-efficacy and interaction with social groups (interactive health literacy) and also lead to greater empowerment (critical health literacy) (Nutbeam, 2000).

Empirical research testing of Nutbeam's (2000) framework of health literacy is limited within the published research literature. This study examined the relationships of functional health literacy, self-efficacy, social support, and empowerment in individuals managing PD.

Literature Review

Parkinson's Disease

Parkinson's disease is a chronic neurodegenerative disorder that is characterized by muscle tremor (PSC, 2011). Other common symptoms include slowed and rigid movement, impaired balance, and tightening of the muscles, however the symptoms vary depending on the individual (PSC, 2011). Healthcare practitioners differentiate a diagnosis of PD as either early onset or late onset. While many commonalities exist among early and late disease onset PD, researchers are also discovering some significant differences. Parkinson's disease is most commonly diagnosed among individuals 50 to 60 years of age (late onset), and research indicates significant physical and mental differences between individuals diagnosed with early onset (less than 40 years of age) versus late onset PD (American Academy of Neurology, 2013).

In 2003, a group of researchers studied the quality of life impact and disease trajectory of early and late onset PD patients (Schrag, Hovris, Morley, Quinn, & Jahanshahi). In this study, early onset was defined as onset before the age of 50 years and late onset was defined as onset after the age of 50 years (Schrag et al., 2003). Using a cross-sectional design, Schrag et al. (2003) measured participants' disease stage and disability, psychosocial function, and marital and socioeconomic status. The findings from this study showed that disease severity and disability were similar for both early and late onset PD patients (Schrag et al., 2003). However, they did find that participants in the early onset group reported more medication-related involuntary movements and marital problems (Schrag et al., 2003). In addition to this, participants in the early onset group experienced higher levels of depression and lower levels of quality of life (Schrag et al., 2003). Based on these findings, Schrag and colleagues concluded that PD has a strong impact on one's life, and particularly for individuals diagnosed before the age of 50 years.

In an earlier research study, Friedman (1994) examined the clinical differences and similarities between early (before the age of 46 years) and late onset PD. Friedman found that compared to late onset PD, people with early onset PD were more likely to experience bradykinesia (slowness of movement) and develop dyskinesia (inability to control movements) as a result of pharmaceutical treatments (e.g., prescribed levodopa). The findings from this study are consistent with those of Schrag et al. (2003).

In 1994, Kostic and colleagues studied the frequency of depression in individuals with early and late onset PD. Kostic et al. found that individuals with early onset PD experienced higher levels of depression compared to those with late onset PD. The findings from Schrag et al. (2003), Friedman (1994), and Kostic et al. provide evidence

that there are many similarities but also important differences between the expressions of early and late onset PD. The reported research evidence indicates significantly greater physical consequences, emotional challenges, and disease severity among individuals diagnosed with early onset PD. This has important consequences in relation to health information and service needs and implications related to the health literacy skills of individuals managing PD. Individuals with limited health literacy skills are less able to effectively manage their own health, access health services, and understand information that supports informed health-related decision-making (Mitic & Rootman, 2012).

Parkinson's Disease and Information Needs

Currently there is very limited research on the information needs of people with PD. Recent research studies have shown that health literacy can affect information-seeking behaviour (Nutbeam, 2008). In 2003, a group of researchers studied the information needs of older people (over 65 years of age) with PD (Macht, Gerlich, Ellgring, & the Infopark Collaboration). Using a qualitative design, Macht et al. interviewed 33 individuals with idiopathic (unknown cause) PD. In this study, more than half of the participants were assessed as having mild to moderate disease severity (Macht et al., 2003). The researchers found that the majority of the participants wanted information about the cause and course of the disease, treatment options, and coping strategies at the time of diagnosis and shortly thereafter (Macht et al., 2003). They also found that participants' information needs changed over the course of the disease. For example, participants' information needs at the time of diagnosis focused on the nature of the disease whereas after diagnosis learning to cope with PD was the main focus (Macht et al., 2003). Macht et al. concluded that the information that is given to patients should be adapted to their information needs. Although this study only included older people

with PD, the findings are helpful in understanding that information needs change over time.

In a similar research study, Theodoropoulou and colleagues (2003) interviewed a small group of older people with PD to understand their information needs before, at the time of, and following initial diagnosis. Similar to Macht et al. (2003), Theodoropoulou et al. found that participants' information needs changed over the course of the disease. For example, participants were interested in the pharmacological management of PD during the initial stages of the disease but less so as the disease progressed (Theodoropoulou et al., 2003). They also found that most of the participants preferred to receive information about their disease through pamphlets, the television, or telephone (Theodoropoulou et al., 2003). Based on these findings, Theodoropoulou et al. recommended that the information needs of people with PD should be considered when developing services and interventions for this population.

In a more recent research study, Williams (2005) also examined the information needs and information-seeking behaviour of people with PD. Participants were asked to complete a questionnaire, which captured information about their information needs, their information-seeking patterns, preferred information sources, and overall level of satisfaction (Williams, 2005). The findings revealed that younger people with PD preferred a wide range of information, including information about the disease, employment, and how to cope with family commitments (Williams, 2005). The researcher also found that compared to older people, younger people with PD were more likely to access information, such as new research findings and information about alternative therapy, on the Internet (Williams, 2005).

Health Literacy

A group of international experts authored the Calgary Charter on Health Literacy, a document that highlights the need for adequate health literacy in order to access health information and services, understand health issues, and navigate the health system (Centre for Literacy, 2008). Health literacy skills have been shown to increase people's control over their health, improve their ability to access information, and impact their ability to assume responsibility for their health (Kickbusch, 2001). Adults with low health literacy were less likely to obtain preventative screening, had less knowledge about their chronic disease, were more likely to have advanced stages of illness at the time of diagnosis, and to experience higher rates of disease mortality (Davis, Williams, Marin, Parker, & Glass, 2002; Garbers & Chiasson, 2004; Williams, Baker, Parker, & Nurss, 1998). As the prevalence of chronic disease continues to rise in Canada, the need for adequate health literacy skills is becoming more important. Recent surveys have shown that one out of every seven Canadians has trouble understanding and using written material, which is very concerning from a healthcare perspective (Statistics Canada, 1998; 2008). In Canada, 60 percent of adults have difficulty obtaining, understanding, and acting upon health information and services (CCL, 2007). The most recent International Adult Literacy Survey (IALS) showed that in Canada there is wide variation in prose, document, and quantitative scores (Statistics Canada, 1998). Differences in scores can be attributed to influencing factors, most notably educational attainment and socioeconomic status (Statistics Canada, 2000).

In this study, health literacy was defined as “the capacity to acquire, understand, and use information in ways which promote and maintain good health” (Nutbeam, 2009, p. 304). This definition aligns with the framework used in the study.

Parkinson's Disease and Health Literacy

To date, very few researchers have studied health literacy in people living with PD. However, in 2010, researchers studied the readability (how easily text can be read and understood) of PD information on the Internet (Fitzsimmons, Michael, Hulley, & Scott). After reviewing nearly 100 websites that contained PD information, Fitzsimmons et al. (2010) found that a large proportion of the websites did not meet population level readability standards as defined by the Flesch-Kincaid formula (readability test). Based on these findings, they recommended that the websites that did not meet readability standards should be revised so that the PD information was accessible to individuals seeking information online (Fitzsimmons et al., 2010). The high readability demands of the PD websites is of even greater concern in light of the reported limited literacy and health literacy skills of Canadians (Mitchell & Begoray, 2010).

In the same year, a group of researchers from the United States examined functional health literacy in a sample of older adults diagnosed with a range of movement disorders (specific disorders not specified) (Armistead-Jehle, Cifu, Wetzel, Carne, & Klanchar, 2010). Armistead-Jehle et al. (2010) administered the Test of Functional Health Literacy for Adults (TOFHLA) to 44 male participants. The researchers found that most of the participants had adequate health literacy skills. They concluded that younger age, greater education, and higher Mini-Mental State Exam (MMSE) scores were identified as contributing factors to higher health literacy skills (Armistead-Jehle et al., 2010). Despite their positive findings, Armistead-Jehle et al. cautioned that limited health literacy skills can be a barrier to effective healthcare delivery and that healthcare professionals need to be cognizant of the critical nature of health literacy. Of the published research to date, the focus has been on assessing the functional health literacy

skills of individuals with PD with little to no attention directed at the broader knowledge, skills, and attributes as proposed contributors to interactive and critical health literacy skills.

Parkinson's Disease and Self-Efficacy

As defined by Albert Bandura (1994), self-efficacy is the self-perception that one can perform in ways that allow some control over life events. Self-efficacy is related to health in that it can influence one's behavior (O'Leary, 1985). For example, self-efficacy may influence an individual's decision on which activities will be attempted or avoided (e.g., exercise, smoking) (O'Leary, 1985). Self-efficacy can be measured as a whole (general self-efficacy) or in relation to a specific task. In this study, self-efficacy will be examined as a generalized trait as opposed to it being related to a specific task. General self-efficacy is the self-belief that one can cope with a variety of demands (Schwarzer & Jerusalem, 1995). Nutbeam (2000) proposed that individuals who have adequate interactive health literacy skills are more motivated and confident in their ability to use a variety of information and services.

In 1997, a large group of researchers from Tokyo studied self-efficacy in people with PD (Fujii et al.). Fujii et al. surveyed a total of 143 participants, which included 73 males and 70 females. Using the General Self-Efficacy Scale (GSES), the researchers found that more than half of the participants had low general self-efficacy (Fujii et al., 1997). Interestingly, participants who had high general self-efficacy were more likely to have stronger social support networks, higher levels of confidence, and better able to cope with daily problems compared with those who had low general self-efficacy (Fujii et al., 1997). Based on these findings, Fujii et al. emphasized the importance of attending to both the social and psychological needs of people with PD. The findings from this study

are helpful in understanding that self-efficacy can be associated with a wide range of factors in this population.

In the last decade there has been a growing interest in the relationship between self-efficacy and self-management in PD. Many researchers have identified a positive relationship between level of self-efficacy and self-management (Eccles & Simpson, 2011; Gallagher, Donoghue, Chenoweth, & Stein-Parbury, 2008). In similar studies, researchers found that individuals with high self-efficacy compared to those with low self-efficacy were more likely to participate in self-management programs such as exercising (Ellis et al., 2011; Nelson, Wong, & Lai, 2011).

Parkinson's Disease and Social Support

Social support is the belief that one is cared for and loved, esteemed and valued, and belongs to a network of communication and mutual obligations (Cobb, 1976). This definition of social support was chosen as it aligns with Nutbeam's (2000) conceptualization of social support.

In a recent research study, McCabe and O'Connor (2012) studied social support in people living with PD. Using a cross-sectional design, they surveyed 100 participants who were recruited from various outpatient departments. Researchers measured social support by the number of family members living in the same household with an individual with PD (McCabe & O'Connor, 2012). McCabe and O'Connor found that the greater number of family members living with the individual with PD was significantly related to self-reported enhanced quality of life in people living with PD.

In an earlier research study, Backer (2000) examined the relationship between social support and health dysfunction in individuals with PD. In this study, social support was defined as the PD clients' self-reported availability of social support and measured

using the Medical Outcomes Study (MOS) Social Support Survey (Backer, 2000). The MOS Social Support Survey (Hays, Sherbourne, & Mazel, 1995) consists of 22 items in total and each item is ranked using a five-point Likert scale (0 – none of the time, 5 – all of the time). Backer found that social support was a strong predictor of health status (e.g., higher social support contributed to better health status) in people living with PD. Together, the findings from McCabe and O'Connor (2011) and Backer are helpful in understanding the importance of social support in PD and that increased social support can lead to better health status in this population.

Parkinson's Disease and Empowerment

Empowerment is a complex, multidimensional concept. Lacking a universally agreed upon definition, empowerment has been described as: (1) having decision-making power, (2) having access to information and resources, (3) having a range of options from which to make choices, and (4) learning to think critically (Chamberlin, 1997).

Empowerment has been identified as a health-enhancing strategy and an important contributor to health (Wallerstein, 1992). In this study, empowerment was defined as “a process through which people gain greater control over decisions and actions affecting their health” (Nutbeam, 1998, p. 354).

Little research has investigated the relationship between empowerment and individuals' experience of PD. However, in 2006, Holloway created and implemented a care pathway to facilitate more organized care for individuals with PD. She found that one of the most positive outcomes of the pathway was patient and caregiver empowerment (Holloway, 2006). Empowerment was achieved through increased capacity to self-manage and easier access to resources (Holloway, 2006). Although empowerment is identified as an outcome, Holloway does not provide a definition of this

construct. These findings are important because empowerment has been identified as an important concept in chronic disease management (Bodenheimer, Lorig, Holman, & Grumbach, 2002). In the health literacy framework, Nutbeam (2000) identifies that individuals who have adequate health literacy skills are enabled to participate in health-enhancing actions leading to individual and community empowerment.

Summary of the Literature

Parkinson's disease is a chronic, neurodegenerative disease that affects the lives of many Canadians. As the prevalence rate of chronic disease including PD continues to rise in Canada, the need for adequate health literacy skills is becoming more important. Health literacy skills constitute an important health determinant particularly for individuals managing a chronic disease such as PD. Yet reports of health literacy skills among PD populations are not evident within the published research literature. As well, health literacy, self-efficacy, social support, and empowerment have all been identified as important factors in relation to PD care management however, the relationships between these variables is poorly understood.

Hypotheses and Rationale

1. It is hypothesized that functional health literacy will be positively associated with self-efficacy in individuals with PD.

This hypothesis is based on recent research findings that there is a relationship between health literacy and self-efficacy in individuals with chronic diseases (Backer, 2000; McCabe & O'Connor, 2011; McCleary-Jones, 2011; von Wagner, Semmler, Good, & Wardle, 2009).

2. It is hypothesized that there is an association between functional health literacy and social support in individuals with PD.

This hypothesis is based on research findings that social support is a strong predictor of health status and quality of life in individuals with PD (Backer, 2000; McCabe & O'Connor, 2012), as well as the proposed relationships between constructs outlined in Nutbeam's (2000) framework.

3. It is hypothesized that functional health literacy will be positively associated with empowerment in individuals with PD.

This hypothesis is based on the finding that empowerment can be achieved by increased capacity to self-manage and easier access to resources (Holloway, 2006).

4. It is hypothesized that self-efficacy will be positively associated with empowerment in individuals with PD.

This hypothesis is based on the proposed relationships between constructs outlined in Nutbeam's (2000) framework.

Methods

Design

Using a non-experimental, cross-sectional design, this study examined the relationships of functional health literacy, self-efficacy, social support, and empowerment in individuals living with PD within the southwestern region of Ontario, Canada. A non-experimental design is fitting given the lack of research into these relationships among individuals managing PD (Polit & Beck, 2008). Ethical approval was attained for the study by the Western University health sciences research ethics board (Appendix A).

Participant Recruitment

Convenience sampling was conducted to recruit participants for this research. Convenience sampling is a type of non-probability sampling, which involves recruiting the most available people as study participants (Polit & Beck, 2008). In this study, the

accessible population was defined as individuals with PD who utilize the resources provided by the PSC and participate in activities organized by the society. The PSC (2011) is an organization that is dedicated to improving the lives of individuals and their families who are affected by PD. This organization was chosen because it is the main organization within Ontario for individuals with PD and their families. Also included in the accessible population were patients from two local family physician offices.

Participant recruitment strategies included advertisement flyers about the study distributed to the Parkinson Society Southwestern Ontario London location, as well as family physician offices. Recruitment advertisements for the study were also distributed at both the Parkinson's Conference in London and Windsor, Ontario. Information about the research was provided to the movement disorder centres in London, Ontario and Kitchener, Ontario.

For inclusion in the study, volunteer participants were required: (1) to be 18 years of age or older, (2) to self-report a diagnosis of PD, (3) to have cognitive capacity to participate in the study as measured by a score of 25 or greater on the MMSE (Folstein, Folstein, & McHugh, 1975), and (4) to be able to read, speak, and write in English. A score of 25 or greater on the MMSE indicates normal cognition (Folstein et al., 1975). Scores less than 25 can indicate cognitive impairment. The MMSE was used in this study to help assess whether participants would be able to adequately complete the study requirements (e.g., surveys).

Sample Size

In order to determine an estimated sample size for this study, a power analysis was conducted using G-Power (Faul, Erdfelder, Lang, & Buchner, 2010). To calculate an estimated sample size for bivariate correlation, the following parameters were used: alpha

level of .05, medium effect size, two variables, and a power of .80 (Cohen, 1992; Lee, 2011). Cohen (1992) describes medium effect size as an effect that is likely observable to a careful observer. A medium effect size approximates the average size of observed effects in many fields and is commonly used when no research is available to assess effect size for the population (Cohen, 1992). Based on the selected parameters, a total sample size of 67 individuals was calculated.

Data Collection

Interested participants contacted the researcher to arrange a face-to-face interview for data collection. All interviews were arranged at a time that was most convenient for participants in order to accommodate the ‘on-off’ cycles (an on cycle is defined as a state where PD symptoms such as muscle tremor are controlled; an off cycle is descriptive of a state of decreased symptom control) associated with PD (Parkinson’s Disease Foundation, 2013; PSC, 2011). Data collection interviews took place in participants’ homes. Each data collection interview lasted approximately 60 minutes. At the beginning of each interview, the study purpose and processes were reviewed again with the participant and any participant questions were addressed. With participant consent, a series of assessment questions were administered that included a demographic questionnaire, two questions that inquired about participants’ information needs and access preferences, two questions that assessed participants’ self-reported social support, the GSES (Schwarzer & Jerusalem, 1995), the Empowerment Scale (Rogers, Chamberlin, Ellison, & Crean, 1997), and lastly, the short form of the Test of Functional Health Literacy in Adults (S-TOFHLA) (Parker, Baker, Williams, & Nurss, 1995). Participants completed the assessment questions independently, however the researcher was present to

respond to any questions. A gift card of \$5.00 for a coffee shop was given to each volunteer participant.

Participants completed a demographic questionnaire (refer to Appendix B). The demographic questionnaire inquired about participants': age, age at diagnosis, gender, level of education, employment status, and income. Inquiry into participants' information needs and preferences included questions regarding where and what type of PD information participants found to be most valuable. Questions related to information needs and access preferences, as well as social support, resulted from the review of the literature and the development of these questions were guided by the conceptual framework (Nutbeam, 2000). For example, inquiry about individuals' participation in support groups, involvement in a public rally or demonstration, and developing or contributing to a petition were intended to address aspects of interactive and critical health literacy. The three additional assessment instruments included the S-TOFHLA (Parker et al., 1995) which was used to measure functional health literacy, the GSES (Schwarzer & Jerusalem, 1995) (refer to Appendix C) which assessed self-efficacy, and the Empowerment Scale (Rogers et al., 1997) (refer to Appendix D) which was used to measure self-reported empowerment.

Functional health literacy. Currently available health literacy assessment tools only assess prose and numeric health literacy skills. There are no formalized or psychometrically tested assessment tools that assess interactive and critical health literacy skills. However, there are a number of functional health literacy assessment tools and the most commonly used instruments include: the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1991), the Newest Vital Sign (Weiss et al., 2005), and the TOFHLA (Parker et al., 1995). The REALM (Davis et al., 1991) is used to assess an

individual's ability to read common medical words. The test consists of 11 items in total however only nine of the items are included in the total score. While this assessment is simple and quick to administer, this tool primarily assesses word recognition and not reading comprehension.

The Newest Vital Sign (Weiss et al., 2005) uses a nutritional label from an ice cream container and patients are asked six questions regarding the information on the label. This tool assesses both prose and numeracy skill. This tool was considered for use however the researcher decided to use the more widely administered S-TOFHLA. The S-TOFHLA (Parker et al., 1995) was used in this study because it also assesses both prose and numeracy skill. Use of the S-TOFHLA is well-documented in the literature so the researcher was able to make comparisons with other study findings. It was important to the researcher to use an assessment tool that aligned with the concepts and definitions used in the theoretical framework.

Functional health literacy was measured using the S-TOFHLA (Parker et al., 1995). The S-TOFHLA measures functional health literacy, which includes numeracy and prose comprehension. There are four numeracy items and 36 prose items on the test, and each item is scored as correct or incorrect (0 – incorrect response, 1 – correct response). The prose items involved filling in the blank using the four options provided. Numeracy items included questions about medication related topics. A total score (range: 0-100) is calculated by multiplying the numeracy and prose comprehension items by seven and four, respectively, to reach a total score out of 100. Participants who score 0 to 53 are considered to have inadequate functional health literacy, those scoring 54 to 66 have marginal functional health literacy, and participants who score 67 to 100 have adequate functional health literacy (Baker, Williams, Parker, Gazmararian, & Nurss,

1999). The reported reliability for the numeracy and reading comprehension items is .68 and .97, respectively (Parker et al., 1995; Baker et al., 1999). This tool has been successfully used in both younger and older populations, as well as various patient populations (e.g., individuals living with Alzheimer's disease or HIV) (Baker et al., 1999; de Oliveira, Porto, & Brucki, 2009).

Self-efficacy. There are various self-efficacy measurement tools available including the GSES (Schwarzer & Jerusalem, 1995), as well as more task-oriented scales such as the Exercise Self-Efficacy Scale (Resnick & Jenkins, 2000). The GSES (Schwarzer & Jerusalem, 1995) was chosen for this investigation over a more task-oriented scale because this study did not examine any one task in particular.

Self-efficacy was measured using the General Self-Efficacy Scale (Schwarzer & Jerusalem, 1995). The GSES is comprised of ten items, and each item is ranked using a four-point Likert scale (1 – not at all true, 2 – hardly true, 3 – moderately true, 4 – exactly true). A total score ranging from ten to 40 is calculated by adding each of the ten item scores together. Higher scores indicate stronger general self-efficacy. The reliability coefficient for the GSES is .80 (Schwarzer & Jerusalem, 1995). This assessment tool has been applied to various populations including healthcare, education, and refugees (Scholz, Dona, Sud, & Schwarzer, 2002). Details of this instrument are given in Appendix C.

Social support. Social support is the belief that one is cared for and loved, esteemed and valued, and belongs to a network of communication and mutual obligations (Cobb, 1976). Social support can be assessed in terms of structural support (number of social ties) or functional support (function in a social group). In this study, social support was assessed by asking participants if they have ever had contact / support from a person

with PD or if they have ever joined a support group. These questions were developed based on the findings from the literature review, as well as the guiding theoretical framework. The MOS Social Support Survey (Hays et al., 1995) is a commonly used social support assessment tool; however, it was not used in this study given the similarity with the items in the GSES.

Empowerment. The Empowerment Scale (Rogers et al., 1997) was used to assess empowerment. More specific empowerment scales do exist such as the Diabetes Empowerment Scale (Anderson, Funnell, Fitzgerald, & Marrero, 2000), however the Empowerment Scale by Rogers et al. (1997) was chosen because it assesses general rather than disease-specific self-reported empowerment. Rogers et al. described empowerment as having control over one's life and achieving personally defined goals.

The Empowerment Scale is made up of 25 items, and each item is ranked using a four-point Likert scale (1 – strongly agree, 4 – strongly disagree). All but items 3, 6, 7, 9, 14, 15, 19, and 20 are reversed scored. A total score is calculated by adding each of the 25 item scores together with a higher score indicating higher self-reported empowerment. The scale is made up of five factors which include: (1) self-esteem / self-efficacy (9 items), (2) power-powerlessness (8 items), (3) community activism and autonomy (6 items), (4) optimism and control over the future (4 items), and (5) righteous anger (4 items). The reported reliability for the Empowerment Scale is .86 (Rogers et al., 1997). This instrument has been used to assess self-reported empowerment among many mental health self-help programs across the United States (Rogers et al., 1997). Details of this instrument are given in Appendix D.

Mini-Mental State Exam. The MMSE is a questionnaire that is used to test mental status / cognition (Folstein et al., 1975). In this study, it was used as a screening

tool. It is made up of 30 questions in total and each item is scored as correct or incorrect (0 – incorrect response, 1 – correct response). A total score (range: 0-30) is calculated by adding each of the 30 item scores together. Based on the total score, participants are classified as having severe (≤ 9), moderate (10-20), or mild (21-24) cognitive impairment. A total score of greater than or equal to 25 indicates normal cognition. However, a score below 25 does not always indicate dementia; a person's mental ability may be affected by other factors (e.g., hearing difficulties) (Alzheimer's Society, 2012). Details of this instrument are given in Appendix E.

Data Analysis

All analyses were conducted using SPSS, Version 20.0 (IBM, 2013). Data were initially reviewed for accuracy of data input. Frequency distributions for continuous variables were reviewed to determine normal distribution (histograms, box plots, stem and leaf diagrams). Descriptive statistics for participant demographics (e.g., age, age at diagnosis, gender, level of education, employment status, income, information needs and access) and participant scores of health literacy, self-efficacy, empowerment, and MMSE were calculated. T-tests were used for comparisons between groups (e.g., gender). Non-parametric statistics were used for categorical data. Assumptions were not met for the Chi-Square analysis therefore the Fisher's Exact Probability Test was used to assess the relationship between categorical variables (e.g., contact / support from a person with PD, member of a support group, functional health literacy). Correlation coefficients were assessed using Pearson product-moment correlation coefficient. A *P* value of 0.05 was used to indicate statistical significance.

Results

Descriptive Results

Thirty-three individuals volunteered to participate in the study. The demographic characteristics of the 33 participants in the study are presented in Table 1. In this sample the average age of participants was 70.52 years ($SD=7.24$) and participants ranged in age from 55 to 84 years at the time of study participation. Individuals with both early and late onset PD were included in the study. Of the 33 participants surveyed, 15 (45.5%) were male and 18 (54.5%) were female. The average age at diagnosis was 59.94 years ($SD=11.99$). The majority of participants were not employed (97%) and approximately 18 % of the participants did not complete high school. The highest level of education completed by participants was an undergraduate or post-graduate university degree (27.3%). Nearly half of participants had an income of less than \$34, 999 each year (42.4%).

Table 1. *Demographic Characteristics*

Demographic	Description	Frequency (<i>n</i>)	Percent (%)
Gender	Male	15	45.5
	Female	18	54.5
Education	Did not complete high school	6	18.2
	High school diploma	8	24.2
	College diploma/Some university	10	30.3
	Completed under-/post-graduate	9	27.3

	university degree		
Employed	Yes	1	3
	No	32	97
Total Income	Up to \$34,999	14	42.4
	\$35,000 to \$74,999	9	27.2
	\$75,000 to more than \$100,000	5	15.2
	Choose not to answer	5	15.2

Table 2. *Participants' Age and Age at Diagnosis*

Demographic	Mean	Range (SD)
Age	70.52	55 – 84 (7.23)
Male	71.47	(6.78)
Female	69.72	(7.24)
Age at diagnosis*	59.94	33 – 80 (11.99)
Male	61	(9.99)
Female	59.11	(11.99)

*N=32

Information and access preferences. Over one third (36.3%) of participants indicated that information related to coping with PD constituted their most important health information needs. Information regarding PD treatment was reported as the second most desired type of information (30.3%), followed by information about the symptoms of PD (18.2%). Participants reported the Internet as their most commonly used source of PD information (48.4%), followed by healthcare professional (18.2%), and books and organizations (9.1%). The majority of participants have had contact with or support from

another person who has PD (81.8%), as well as joined a support group (97%). This data can be found in Table 3.

Table 3. *Information Access and Preferences*

Demographic	Description	Frequency (<i>n</i>)	Percent (%)
Preferred Types of PD Information	Causes of Parkinson's disease	1	3
	Coping with daily life	2	6.1
	Prognosis of Parkinson's disease	2	6.1
	Symptoms of Parkinson's disease	6	18.2
	Treatment of Parkinson's disease	10	30.3
	Coping with Parkinson's disease	12	36.3
Preferred Sources of PD Information	Brochures / Pamphlets	1	3
	Family / Friends	2	6.1
	Books	3	9.1
	Organizations	3	9.1
	Healthcare professional	6	18.2
	Internet	16	48.4
	Other	2	6.1
Contact / support from a person with Parkinson's disease*	Yes	27	81.8
	No	6	18.2

Joined a support group	Yes	32	97
	No	1	3
Participated in organized rally / campaign	Yes	27	81.8
	No	6	18.2
Created a petition	Yes	5	15.2
	No	28	84.8
Letter to local newspaper	Yes	13	39.4
	No	20	60.6

* “Have you ever had contact with or support from another person who has PD?”

Health literacy profile of participants. For participants in this study the mean combined score (numeracy and prose) on the S-TOFHLA was 77.21 ($SD=21.65$) indicating adequate functional health literacy. The mean combined score for males was 75.4 and 78.7 for females. Participants’ scores ranged from 28 to 100. Scores from the S-TOFHLA were collapsed into three broad categories of inadequate (0-53), marginal (54-66), and adequate (67-100) functional health literacy (Baker et al., 1999). In total, there were 6 (18.2%) participants with inadequate health literacy, 5 (15.1%) with marginal health literacy, and 22 (66.7%) with adequate health literacy. Approximately one third (inadequate at 18.2% and marginal at 15.1% = 33.3%) of study participants are challenged with limited functional health literacy skills. The frequencies and percentages of the three health literacy categories are presented in Table 4. The Cronbach’s alpha for the prose scale was .95 and .65 for the numeracy scale.

Table 4. *Health Literacy Scores of Participants*

Level	Frequency (<i>n</i>)	Percent (%)
Inadequate (0-53)	6	18.2
Marginal (54-66)	5	15.1

Adequate (67-100)	22	66.7
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Participant self-efficacy. Participants in this study reported as having moderately high levels of general self-efficacy ($M=28.28$, $SD=5.9$). Participants' scores ranged from 18 to 40. The mean score for males and females was 29.2 and 27.88, respectively. Although the mean score for this scale indicates a higher level of general self-efficacy, some of the participants scored as low as 18, which is indicative of lower general self-efficacy. The Cronbach's alpha for this scale was .88.

Participant empowerment. In this study the mean score on the Empowerment Scale was 2.99 indicating a moderately high level of empowerment (range: 1-4). Participants' scores ranged from 2.48 to 3.6. The mean score for males and females was 2.13 and 2.06, respectively. The mean score and standard deviation for each of the five factors are as follows: self-esteem / self-efficacy ($M=3.12$, $SD=.41$), power-powerlessness ($M=2.75$, $SD=.32$), community activism and autonomy ($M=3.35$, $SD=.37$), optimism and control over the future ($M=2.92$, $SD=.46$), and righteous anger ($M=2.13$, $SD=.55$). The Cronbach's alpha for this scale was .77.

Mini-Mental State Exam. The mean score on the MMSE was 27.27 ($SD=1.89$) indicating normal cognition. Based on these scores, the researcher included all 33 participants' data in the analysis. The Cronbach's alpha for this scale was .21. The Cronbach's alpha is not commonly calculated for the Mini-Mental State Exam because it is mainly used in the clinical setting. The mean, standard deviation, and reliability coefficient was calculated for each study variable and can be found in Table 5.

Table 5. *Descriptive Results of Participants' Functional Health Literacy, Self-Efficacy, Empowerment, and MMSE Scores*

Variable	Mean	SD	Cronbach's Alpha
S-TOFHLA (Prose)	32.45	6.52	.95
S-TOFHLA (Numeracy)	14.30	2.37	.65
GSES	28.48	5.9	.88
Empowerment	2.99	.28	.77
MMSE	27.27	1.89	.21

Test of Hypotheses

Functional health literacy and general self-efficacy. There was a significant small, positive correlation between functional health literacy and general self-efficacy ($r=.13, n=33, p <.05$), with higher scores of functional health literacy associated with greater general self-efficacy. This relationship was examined using Pearson product-moment correlation coefficient. Therefore, the hypothesis that functional health literacy is positively associated with general self-efficacy in individuals with PD was supported.

Functional health literacy and social support. This relationship was examined using Fisher's Exact Probability Test. The two categories of functional health literacy (inadequate / marginal and adequate) were used. Social support was assessed with a question regarding contact / support from a person with PD. The Fisher's Exact Probability Test indicated a significant association between functional health literacy and social support ($n=33, p=.01, phi=-.5$), therefore the hypothesis was supported.

Functional health literacy and empowerment. This relationship was also examined using Pearson product-moment correlation coefficient. There was a significant small, positive correlation between functional health literacy and empowerment ($r=.20,$

$n=33, p <.05$), with higher scores of functional health literacy associated with greater self-reported empowerment. Thus, the third hypothesis was supported.

General self-efficacy and empowerment. This relationship was examined using Pearson product-moment correlation coefficient. There was a significant medium, positive correlation between general self-efficacy and empowerment ($r=.496, n=33, p <.05$), with greater general self-efficacy associated with higher self-reported empowerment. Thus, the fourth and final hypothesis was supported.

Discussion

The purpose of this research study was to assess the health literacy skills and information needs of individuals managing PD and to examine the relationships of functional health literacy, self-efficacy, social support, and empowerment in this same population of Canadian adults. The hypothesized relationships between functional health literacy, self-efficacy, social support, and empowerment in this sample of individuals living with PD were supported in this study.

Participants in this study identified information related to coping with PD, PD treatment, and PD symptoms as their most important information needs. These findings are similar to previous research studies (Macht et al., 2003; Theodoropoulou et al., 2003; Williams, 2005) which also identified information related to coping and treatment as important to people living with PD. The most commonly used sources for PD information included the Internet, healthcare professionals, and books and organizations. This finding is different from that of Theodoropoulou et al. (2003) who found that older people with PD prefer to receive information through pamphlets, the television, or by telephone. Williams (2005), however, also identified the Internet as a commonly used source of PD information for younger people with PD. These findings align with the

results from the 2005 Canadian Internet Use Survey (CIUS) (Statistics Canada, 2008) which revealed that of the 16.8 million Canadians surveyed, more than half used the Internet to search for medical or health-related information. The survey also showed that Canadians over the age of 45 years were most interested in information on specific diseases and medications (Statistics Canada, 2008). The use of the Internet to search for medical or health-related information has increased over the years, rising from 57.9% in 2005 to 69.9% in 2009 (Statistics Canada, 2010). As the expectation of self-care management increases and the need for health information and services grows, it is suspected that the Internet will be a primary source of information for people living with a chronic disease. Many people have added the Internet to their list of resources (Pew Internet, 2013).

Health Literacy Framework

Proposed variables within Nutbeam's (2000) framework of functional, interactive, and critical health literacy align with improved knowledge, self-efficacy, interaction with others (e.g., social groups) and empowerment. In this study, there was a significant, positive correlation between functional health literacy and self-efficacy, functional health literacy and empowerment, and self-efficacy and empowerment. Additionally, there was a significant association between functional health literacy and social support. These findings provide support for Nutbeam's health literacy framework. An empirically tested theoretical framework is important in developing and guiding future research and useful in the development of intervention and evaluation strategies. Many research studies cite and use Nutbeam's health literacy framework, however empirical testing of the framework does not exist within the research literature.

Most study participants had adequate functional health literacy skills; however, approximately one third of participants scored as having marginal or inadequate functional health literacy skills. This finding is similar to Armistead-Jehle et al.'s (2010) finding that the majority of their sample (older adults diagnosed with a range of movement disorders) had adequate health literacy skills. Armistead-Jehle et al. identified younger age, greater education, and higher MMSE scores as contributing factors to higher health literacy skills. In the present study participants scored high on the MMSE ($M=27.27$) which could be a contributing factor to higher health literacy skills. However, caution is advised in interpreting this finding because individuals with low health literacy skills may be less inclined to participate in research studies because they may feel ashamed of their lack of literacy skills and have lower self-confidence in their ability to participate (Gazmararian et al., 1999).

Self-efficacy can affect both health and health behaviour in many ways. For example, perceived self-efficacy can impact decision-making, as well as the amount of time and effort devoted to a particular task (e.g., seeking out information, exercising) (O'Leary, 1985). Self-efficacy is important in terms of functional health literacy because an individual's ability to find, read, understand, and communicate health-related information may be influenced by their confidence in their ability to perform these tasks (Colbert, Sereika, & Erlen, 2013). In this study there was a significant, positive correlation between functional health literacy and self-efficacy. This finding is similar to von Wagner et al.'s (2009) finding that lower health literacy is associated with less self-efficacy for colorectal cancer screening. von Wagner et al. assessed health literacy using the British version of the TOFHLA. This finding is also consistent with an earlier study that examined the relationship between self-efficacy and self-management behaviour in

an urban, diverse, low-income diabetic population with limited health literacy (Sarkar, Fisher, & Schillinger, 2006). Sarkar et al. (2006) found that self-efficacy scores were consistent with health literacy levels. Additionally, self-efficacy has been examined as a mediating factor in the relationship between literacy level and medication adherence (Wolf et al., 2007). Wolf et al. (2007) found that self-efficacy mediated the impact of low literacy on medication adherence in individuals living with HIV. The findings from the present study indicate that when assessing functional health literacy in individuals living with PD it is important to consider perceived self-efficacy as it may affect their ability to find, read, understand, and communicate health-related information. As well, the findings from this study are helpful in understanding that self-efficacy may be an appropriate target of education for individuals with PD. Individuals managing PD are often required to perform tasks that involve the use of functional health literacy skills (e.g., taking medication or booking appointments) so it is important for them to be confident in their ability to do so.

Social support can have a significant impact on health and health outcomes, especially in older adults. Research studies have shown that older adults often rely on the support from family members when making health-related decisions and that social support can positively affect their overall health (Lee, Arozullah, Cho, Crittenden, & Vincencio, 2009). Social support is important in terms of functional health literacy because it may help to alleviate some of the challenges associated with low functional health literacy (e.g., difficulty reading) (Lee et al., 2009). In this study, there was a significant association between functional health literacy and social support. The findings from this study are similar to that of Lee, Gazmararian, and Arozullah (2006). Lee et al. (2006) investigated health literacy and social support in older adults. They found that

compared to the group with high health literacy levels, participants with low health literacy levels were more likely to receive support (e.g., medical information and reminders). The findings from the present study are significant because they are helpful in understanding the importance of social support in PD. These findings suggest that there is an association between functional health literacy and social support in individuals with PD. Albeit significant, the direction of this relationship in the PD population is not yet known. In arthritis patients, however, Ellis, Mullan, Worsley, and Pai (2012) found that health information-seeking behavior was mediated by their level of health literacy and access to sources of information through their social networks. Because social support was assessed by asking participants if they have ever had contact with or support from another person who has PD, the findings are important because it may be that by being in contact with or receiving support from another person who has PD enhances one's access to information about PD such as information about living with PD and PD services. Future research is needed, however, to better understand the relationship between functional health literacy and social support in individuals with PD.

Empowerment has been described as a health-enhancing strategy and an important contributor to health (Wallerstein, 1992). Empowerment as a contributor to health can lead to change in the social and / or organizational environment which in turn leads to improvements in health (Laverack, 2006). Laverack (2006) describes empowerment as an individual's connectedness with others and their participation in groups whose goal is to create change in their community. In the health literacy framework, Nutbeam (2000) identifies two aspects of empowerment, which include individual and community. Through the development of health literacy skills, Nutbeam (1998) believed that individuals had more control over his / her life (individual empowerment) and that

together individuals can act collectively to address issues affecting their community (community empowerment). In this study there was a small, positive correlation between functional health literacy and empowerment. This finding is of importance because it indicates that individuals who have stronger functional health literacy skills may be more inclined to take action to improve their own personal and community health. In the health literacy framework empowerment is linked to critical health literacy however it is difficult to assess critical health literacy as there is no assessment tool available (Nutbeam, 2000). More research is needed to better understand the relationship between health literacy and empowerment and possible contributing factors.

Limitations

One of the main limitations of this study is that the majority of participants have been or currently are a member of a support group. This limits the generalizability of the results to individuals with PD who are not a part of a support group. Another limitation of this study is that the sample included a combination of early and late onset PD. The researcher acknowledges that there may be fundamental differences between the two groups so it is important to do further research to determine if differences exist. Additionally, there is potential for response bias due to the use of self-report surveys (Polit & Beck, 2008). For inclusion in the study all participants were required to speak and understand English. Participants with PD whose preferred language is not English are not represented and may have different health information needs and skills. A final limitation of the study is the sample size. The researcher was unable to recruit the desired number of participants (67) because of challenges related to participant recruitment despite the diverse recruitment strategies used (e.g., attended a conference and numerous support group meetings, distributed flyers, met with gatekeepers).

Implications for Practice

The findings of this study could be used to guide interactions between healthcare professionals and individuals with PD. When interacting with all clients but particularly with individuals with limited health literacy skills, nurses and other healthcare professionals can use the “talk back” technique (Kripalani & Weiss, 2006). The “talk back” technique allows healthcare professionals to confirm individuals’ understanding of information that has been discussed (Kripalani & Weiss, 2006). Given that the interaction between healthcare professionals and patients is a fundamental aspect of chronic disease management, it is important for healthcare professionals to be able to accurately assess and tailor the care they provide based on patients’ level of health literacy skill. As well, these findings inform providers of the PD information needs and access preferences that can support the development of educational materials for individuals managing PD. Further research is needed to better understand the health literacy skills and possible related factors in the PD population.

Conclusion

The results of this study provide support for the theoretical propositions outlined in Nutbeam’s (2000) health literacy framework. Functional health literacy was positively correlated to self-efficacy and empowerment in individuals living with PD, and positively associated with social support. The findings from this study can be used in clinical practice to develop programs and services for individuals living with PD. More research is needed, however, to better understand the proposed relationships in Nutbeam’s health literacy framework.

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Chapter Three

The purpose of this research study was to assess the health literacy skills of older adults managing PD and to examine the relationships of functional health literacy, self-efficacy, social support, and empowerment in individuals living with PD. There was a total of 33 participants included in the study with an average age of 70.5. As hypothesized, there was a significant, positive correlation between functional health literacy and self-efficacy, functional health literacy and empowerment, and lastly, self-efficacy and empowerment. In addition, there was a significant association between functional health literacy and social support. The theoretical, education, practical, policy, and research implications of these findings are discussed below.

Theoretical Implications for Health Literacy

In this study there was a significant, positive correlation between functional health literacy and self-efficacy, functional health literacy and empowerment, and self-efficacy and empowerment. Additionally, there was a significant association between functional health literacy and social support. These findings provide support for Nutbeam's (2000) health literacy framework which specifies that improved knowledge, which is an indicator of functional health literacy, may enable improved self-efficacy and interaction with social groups and also lead to greater empowerment. Many research studies cite and use Nutbeam's health literacy framework, however it has not yet been empirically tested. An empirically tested theoretical framework is important in developing and guiding future research, as well as in the development of intervention and evaluation strategies. This study demonstrated that in individuals managing PD, higher scores of functional health literacy are associated with greater self-efficacy and empowerment. It also demonstrated that functional health literacy is associated with social support.

Implications for Education

The findings of this study could be used to help educate healthcare professionals on the concept of health literacy. Healthcare professionals play a vital role in explaining treatment plans to patients so it is important for them to be able to assess and adequately address health literacy in their daily practice. These findings could also be used to educate individuals managing PD and their families. Educating individuals with PD and their families on the concept of health literacy and possible related factors may strengthen their ability to access appropriate resources. Education could take place at various times such as during medical appointments or support group meetings. Healthcare professionals are ideally positioned to educate patients on how to evaluate health information and to connect them with proper resources that align with their health literacy skills.

Implications for Practice

The findings of this study suggest that Nutbeam's (2000) health literacy framework can be used to facilitate the development of programs and services for individuals living with PD. More specifically, future programs that focus on strengthening functional health literacy skill, self-efficacy, and social support may lead to greater empowerment in those living with PD. Programs and services that focus on these four concepts would be beneficial for this population.

The findings of this study may also assist healthcare professionals in understanding health literacy and how it relates to health. By raising awareness about health literacy and how it can affect everyday situations, healthcare professionals may be more inclined to assess and act upon health literacy in their daily practice. Possible

strategies for raising awareness could include integrating health literacy into curriculums or hosting in-services in the healthcare field.

The findings of this study could also be used to guide interactions between healthcare professionals and individuals with PD. When interacting with all clients but particularly with individuals with limited health literacy skills, nurses and other healthcare professionals might consider using the “talk back” technique (Kripalani & Weiss, 2006). The “talk back” technique allows healthcare professionals to confirm individuals’ understanding of information that has been discussed (Kripalani & Weiss, 2006).

Nurses play a key role in explaining treatment plans to patients, as well as to family members (Canadian Public Health Agency [CPHA], 2013). Through constant interactions with patients, nurses are ideally situated to identify gaps in patient’s understanding of their health and health needs, and identify those who may have inadequate health literacy skills. There are several strategies that healthcare professionals can use in the clinical setting to assist patients in better understanding their health and health needs. For example, healthcare professionals can assist patients in accessing health information through various outlets such as the Internet (CPHA, 2013). In doing so, patients may be less reliant on print sources such as pamphlets or brochures (CPHA, 2013). Healthcare professionals can also address health literacy in clinical practice by ensuring that print teaching materials are written at a level that is appropriate for the patient receiving them (CPHA, 2013).

Implications for Policy

The findings of this study can be used to educate and influence policymakers. The Expert Panel on Health Literacy identified the need for comprehensive policies and

programs to reduce inequities in health literacy and healthcare access among Canadians (Rootman & Gordon-El-Bihbety, 2008). The findings of this study could be used to raise awareness of the importance of health literacy and how it relates to health among stakeholders. Disseminating the findings to the government could potentially lead to the establishment of health literacy learning standards. As well, by educating stakeholders on the relationships of functional health literacy, self-efficacy, social support, and empowerment, they may be more inclined to increase funding for research on health literacy.

Implications for Further Research

This research study was the first to examine the relationships of functional health literacy, self-efficacy, social support, and empowerment in individuals living with PD. This study specifically focused on developing a greater understanding of Nutbeam's (2000) health literacy framework. Future research should investigate the relationships of functional health literacy, self-efficacy, social support, and empowerment in greater detail and various populations. This would allow for a greater understanding of how these concepts are related. Additionally, investigating the relationships between these variables would allow for a greater understanding of Nutbeam's health literacy framework.

In addition to examining Nutbeam's (2000) health literacy framework in greater detail, it would be beneficial to explore the information and access needs of this population with greater depth. The findings of this study revealed that participants use the Internet as their primary source of PD information. This is particularly concerning for individuals with low health literacy skills as they may have limited access to Internet-based information. As well, they may be at greater risk for misusing and misinterpreting the information they find. Future research should investigate the most commonly used

websites and how individuals understand and personally apply the information they have found. This study illuminated some of the information and access needs of individuals living with PD; however, more research is needed to better understand their needs.

Another area of research requiring more attention is the health literacy skill of the caregivers of individuals living with PD. At the time of data collection, the researcher observed that caregivers play a vital role in the everyday lives of these individuals. As the emphasis of self-management in chronic disease continues to increase, it would be beneficial to understand the level of health literacy skill, as well as the information and access needs, of the caregivers of individuals living with PD.

Conclusion

The results of this study provide support for the theoretical propositions outlined in Nutbeam's (2000) framework of health literacy. In this sample of individuals living with PD, higher scores of functional health literacy were associated with greater self-efficacy and empowerment. As well, functional health literacy was associated with social support. These findings suggest that having improved knowledge, which is an indicator of functional health literacy, may enable improved self-efficacy and interaction with social groups and also lead to greater empowerment. Developing and implementing programs and services to strengthen functional health literacy, self-efficacy, social support, and empowerment, may play a role in improving these factors in individuals living with PD.

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Appendix A

Research



Use of Human Participants - Ethics Approval Notice

Principal Investigator: **Dr. Lorie Donelle**

Review Number: **18586E**

Review Level: **Delegated**

Approved Local Adult Participants: **80**

Approved Local Minor Participants: **0**

Protocol Title: Health Literacy of Individuals Living with Parkinson's Disease

Department & Institution: Nursing, University of Western Ontario

Sponsor:

Ethics Approval Date: December 05, 2011

Expiry Date: October 31, 2012

Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version	Date
UWO Protocol			
Letter of Information & Consent			2011/10/12
Advertisement			

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

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

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

The Chair of the HSREB is Dr. Joseph Gilbert. The UWO HSREB is registered with the U.S. Department of Health & Human Services under the IRB

Appendix B

Study ID _____

Demographic Profile

Please answer the following to the best of your ability. If you do not feel comfortable answering a question, please leave it blank.

1. What was your age at your last birthday? _____

2. What is your gender?
 Male Female

3. At what age were you diagnosed with Parkinson's disease? _____

4. What is the highest level of education you have completed? (Please check one)
 - Elementary school (grade 8 or less)
 - Some high school
 - High school diploma
 - College / Trade diploma
 - Some university
 - Bachelor's degree
 - Graduate degree
 - Other: Please specify: _____

5. Are you currently employed?
 Yes No

6. What is your total income from all sources? (Please check one)
 - Less than \$14,999
 - \$15,000 to \$34,999
 - \$35,000 to \$54,999
 - \$55,000 to \$74,999
 - \$75,000 to \$99,999
 - More than \$100,000
 - Choose not to answer

7. If you are looking for Parkinson's disease information, where do you look? (Please rank your top 3 preferences as 1, 2, and 3)
 - Books
 - Brochures/pamphlets
 - Family/friends
 - Health care professional
 - Internet
 - Organizations
 - Other

8. What type of Parkinson's disease information do you look for? (Please rank your top 3 preferences as 1, 2, and 3)

- Causes of Parkinson's disease
- Coping with Parkinson's disease
- Coping with daily life (e.g., work, family)
- Prognosis of Parkinson's disease
- Symptoms of Parkinson's disease
- Treatment of Parkinson's disease
- Other

9. Have you ever had contact with or support from another person who has Parkinson's disease?

- Yes No

10. Have you ever joined a support group?

- Yes No

If your response is NO, please go to question 11.

If YES, please answer question 10a, 10b, 10c, and 10d.

10a. How many support groups (e.g., face-to-face or online) have you participated in?

- 1-2
- 3-4
- 5 or more

10b. How long have you participated in support group(s) for?

- Attended one session and did not return
- Attended 1-3 support sessions
- Attended 4-6 support sessions
- Attended 7-9 support sessions
- Attended 10 or more support sessions

10c. What is your preferred format of the support group?

- Online
- Face-to-face
- Either online or face-to-face

10d. How would you describe the organization of your support group?

- Formal (e.g., organized by the Parkinsons Society of Canada)
- Informal (e.g., group of friends, online Facebook group)

11. Have you ever participated in an organized rally or campaign for an issue that was meaningful to you?

- Yes No

12. Have you ever created a petition for an issue that was meaningful to you?

Yes No

13. Have you ever written a letter to the local newspaper about an issue that was meaningful to you?

Yes No

Appendix C

For the following questions, please circle the response that best applies to your management of Parkinson's disease. Please use the scale from 1 to 4 to indicate your response.

1 = Not at all true	2 = Hardly true	3 = Moderately true	4 = Exactly true
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1. I can always manage to solve difficult problems if I try hard enough.

1 2 3 4

2. If someone opposes me, I can find the means and ways to get what I want.

1 2 3 4

3. It is easy for me to stick to my aims and accomplish my goals.

1 2 3 4

4. I am confident that I could deal efficiently with unexpected events.

1 2 3 4

5. Thanks to my resourcefulness, I know how to handle unforeseen situations.

1 2 3 4

6. I can solve most problems if I invest the necessary effort.

1 2 3 4

7. I can remain calm when facing difficulties because I can rely on my coping abilities.

1 2 3 4

8. When I am confronted with a problem, I can usually find several solutions.

1 2 3 4

9. If I am in trouble, I can usually think of a solution.

1 2 3 4

10. I can usually handle whatever comes my way.

1 2 3 4

Appendix D

Instructions: Below are several statements relating to one's perspective on life and with having to make decisions. Please circle the number above the response that is closest to how you feel about the statement. Indicate how you feel now. First impressions are usually best. Do not spend a lot of time on any one question. Please be honest with yourself so that your answers reflect your true feelings.

PLEASE ANSWER ALL QUESTIONS
BY CIRCLING THE NUMBER THAT BEST DESCRIBES HOW YOU FEEL.
PLEASE CHECK ONLY ONE.

1. I can pretty much determine what will happen in my life.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

2. People have more power if they join together as a group.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

3. Getting angry about something never helps.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

4. I have a positive attitude toward myself.

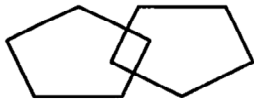
1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

Appendix E

Mini-Mental State Examination (MMSE)

Patient's Name: _____ Date: _____

Instructions: Score one point for each correct response within each question or activity.

Maximum Score	Patient's Score	Questions
5		"What is the year? Season? Date? Day? Month?"
5		"Where are we now? State? County? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible.
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, ...) Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
3		"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (Written instruction is "Close your eyes.")
1		"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)
1		"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.) 
30		TOTAL

Curriculum Vitae

Name: Nicole D. LeBlanc

Post-Secondary Education and Degree: University of Western Ontario
London, Ontario, Canada
2006-2010, BScN

Honours and Awards: Dean's Honour List
MScN Program – Year One

BScN with Distinction
2010

Sigma Theta Tau International Member
2009

Related Work Experience

Registered Nurse
The Hospital for Sick Children
2012-Present

Teaching Assistant
University of Western Ontario
2011-2012

Research Assistant
London Health Sciences Centre
2010-2012