UNDERSTANDING NEED AND EXAMINING BARRIERS AND FACILITATORS TO INTEGRATING PALLIATIVE CARE FOR PARKINSON'S DISEASE:

A MIXED METHODS STUDY

by

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(Under the Direction of Jennifer L. Gay)

ABSTRACT

Parkinson's disease (PD) is the second most common neurodegenerative disorder, characterized by a variety of motor and non-motor symptoms. As the disease is incurable, treatment is palliative in nature, focusing on symptom management and quality of life. Although neurologists apply a basic palliative approach in their treatment of PD, little is known about unmet palliative needs of PD patients that may be better met by specialist palliative care. The purpose of this study is to determine the unmet palliative needs of PD patients and to understand barriers and facilitators of palliative service use. This study aims: 1) to determine the unmet palliative needs of PD patients, and to examine patient-physician agreement on need; 2) to understand how unmet palliative needs affect PD patient quality of life; 3) to understand PD patients' perceptions of palliative need; and 4) to examine physician-perceived costs and benefits of referring PD patients to palliative care using Social Exchange Theory.

In this mixed-methods study, PD patients (n=49) and neurologists (n=62) completed an online survey on the palliative needs of PD patients generally unmet by standard neurological care. Neurologists were also asked about their palliative referral practices and their attitudes towards palliative care. Twenty-three PD patients were also interviewed in person to better understand patient experiences of palliative need and other factors affecting the quality of care.

Nearly all patients experienced some unmet palliative need. Neurologists reported spiritual needs as most unmet while patients emphasized gaps in psychological need. Physical and psychological unmet needs significantly predicted patient quality of life. Patients noted education and care coordination needs as having pervasive effects on the quality of care, and support groups and spiritual care were emphasized as major supports in coping. Patients also reported using their physicians for medication management alone, potentially limiting the psychosocial benefits they may receive from neurology clinics. Perceived pros and cons of palliative care were predictive of physician referrals, highlighting opportunities for education to improve use of the services. Findings from the study are discussed in the context of existing literature and recommendations are made for clinical care and education programs.

INDEX WORDS: Palliative, palliative care, Parkinson’s disease, social exchange theory, neurologist, referral, mixed-methods

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DEDICATION

This work is dedicated to my husband, Tim, and my daughter, Zelle.

You are my inspirations.

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CHAPTER 1

INTRODUCTION

Background

The prevalence of Parkinson's disease (PD) is growing, projected to affect 1.34 million individuals by 2050 (Kowal, Dall, Chakrabarti, Storm, & Jain, 2013). PD is a common neurodegenerative disorder, second only to Alzheimer's disease. It is characterized by a complex variety of motor (e.g., tremors, postural instability, rigidity) and non-motor (e.g., cognitive issues and neuropsychiatric issues) symptoms (Langston, 2006; Lees, Hardy, & Revesz, 2009; Tolosa, Wenning, & Poewe, 2006). The chronic nature of the disease complicates ongoing treatment, which can last up to ten years or more, and a palliative approach is recommended and needed for optimal care outcomes (Bunting-Perry, 2006; Hudson, Toye, & Kristjanson, 2006; Hughes, Daniel, Blankson, & Lees, 1993). The complexity of treatment, as well as the high economic burden of the disease, highlight the need to streamline current care by determining the needs of PD patients that may be best treated by palliative care specialists (Kowal et al., 2013).

Palliative care is a medical specialty that focuses on addressing symptoms in a holistic manner by considering the physical, social, emotional, and spiritual well-being of the patient (National Guideline Clearinghouse, 2013). It aims to improve quality of life for patients with serious advanced illness and their families (*Dying in America*, 2014). Palliative services also coordinate care for patients seeing multiple providers (Morrison & Meier, 2004; National Guideline Clearinghouse, 2013). It has been shown to reduce health care costs and improve clinical outcomes for patients with chronic and terminal illnesses (Morrison et al., 2008; Temel et al., 2010). Despite this, many healthcare providers as well as patients associate palliative care with end-of-life care only, inhibiting appropriate referrals to the service (Fadul et al., 2009).

Although PD treatments are inherently palliative in nature, many PD patients do not experience interdisciplinary, palliative team care until they enter into hospice late in the disease progression, rather than earlier in the disease course (Centers for Medicare & Medicaid Services, 2009). Numerous palliative needs have been identified for PD populations (Bunting-Perry, 2006; Hudson et al., 2006). However, the palliative needs of PD patients unmet through standard neurological care have not been explored, and the barriers to palliative usage by PD patients have not been examined (Hudson et al., 2006).

The social ecological model for health promotion provides a framework that describes how behavior both affects and is affected by the social environment. To most effectively understand and influence behavior, we must understand the social ecological context in which behavior occurs (Bronfenbrenner, 1997; McLeroy, Bibeau, Steckler, & Glanz, 1988). The ecological system consists of five levels of influence: intrapersonal factors, interpersonal processes and groups, institutional factors, community factors, and public policy (McLeroy et al., 1988). Social Exchange Theory is a value expectancy that operates with factors at the interpersonal and institutional levels of the social ecological framework. It asserts that individuals are motivated to perform a behavior or engage in an interaction if they expect a positive outcome from the exchange, and in the current project, it may provide insight into the physician referral process (Shortell & Anderson, 1971). By understanding the interplay of these ecological factors, researchers may be able to affect the behavior change of individuals. The current study will use the social ecological framework as well as social exchange theory to better understand the various factors influencing palliative care use by PD patients.

Purpose of the Study

Given the growing population of PD patients and their interdisciplinary needs, there is an imperative need to understand the unmet palliative needs of PD patients by disease stage and to understand the barriers and facilitators to outpatient palliative referrals. The rationale for this project is that its successful completion may provide new knowledge that can facilitate the integration of both neurologists and outpatient palliative care services early in the course of PD, potentially reducing the costs of care and improving the clinical outcomes and quality of life of PD patients. Because PD can have such a long duration of progression, with different symptoms and needs throughout, it is important to understand the unmet palliative needs to determine the clinical specialty with the most appropriate skills to address each need as it arises. The purpose of this mixed methods study is to determine the unmet palliative needs of PD patients and to understand patient- and provider-based barriers and facilitators of palliative services use.

Specific Aims

Specific Aim 1

To determine the unmet palliative needs of PD patients, and to understand the extent to which PD patients and neurologists agree on these needs. The first hypothesis is that non-physical categories will have more unmet need than the physical need category. The second hypothesis is that PD patients and neurologists will not agree on the unmet palliative needs of patients. PD patients will report greater unmet need.

Sub-Aim 1

To understand how unmet palliative needs affect PD patient quality of life. The hypothesis is that these unmet palliative needs negatively impact PD patient quality of life.

Specific Aim 2

To understand PD patients' knowledge, awareness, and perceptions of palliative need.

This aim will focus on PD patient experiences and perceptions of symptoms and palliative need. This aim will also examine palliative need and factors affecting care at the individual-, interpersonal-, institutional-, community-, and policy-levels of the social ecological framework.

Specific Aim 3

To examine physician-perceived costs and benefits of referring PD patients to palliative care using Social Exchange Theory. In this aim, different constructs of Social Exchange Theory will be explored to understand the potential likelihood of neurology referrals to outpatient palliative care services. The hypothesis is that neurologists perceive more costs than benefits to palliative referrals, and this limits their non-terminal palliative referrals for PD patients.

Innovation

The proposed study is innovative in several ways: 1) it focuses on a topic that has been unexplored up to now by translating research on palliative care and cancer patients to a neurodegenerative population; 2) it applies the use of Social Exchange Theory to physician referrals to collaborative specialties; 3) it applies a mixed methods approach to a topic previously explored either quantitatively or qualitatively, allowing for a more comprehensive understanding of the palliative needs of PD patients.

The information from this study may lead to the development of a model of palliative care for PD. Similar research has been conducted in early palliative care implementation in a cancer population (Temel et al., 2010), and a separate study is underway to develop a model of care for HIV and early non-terminal palliative care (Holstad & Quest, 2014). However, at this time there is no available model of outpatient palliative care for PD patients. Social Exchange

Theory has been used previously to examine physician referrals to other physicians for one-time consultations (Shortell, 1974; Shortell & Anderson, 1971). No study, though, has looked at factors influencing physician referrals to specialties for collaborative and complementary care. The proposed research project has significant positive implications for the field of Public Health because it aims to alter the standard care practices for PD by providing information to facilitate the clinical collaboration between the specialties that can most effectively treat the disease over time.

CHAPTER 2

LITERATURE REVIEW

Palliative Care

With improvements in medical treatments over the last century, chronic conditions, such as Parkinson's disease, can last from several years to several decades (Rao, Anderson, & Smith, 2002). These long-term conditions can require a multitude of clinicians for different issues, and successful management can be very complicated (Norris, Glasgow, Engelgau, O'Connor, & McCulloch, 2003). The Institute of Medicine has recommended research into improving care coordination for individuals with chronic illness as well exploring new models of service delivery that can improve care for patients with complex conditions (Boult et al., 2009).

Palliative care is a medical service that provides interdisciplinary, holistic care focused on symptom management and improving quality of life (Meyers & Linder, 2003; National Guideline Clearinghouse, 2013). It addresses pain and disease symptoms through physical, psychological, social, and spiritual care (Meyers & Linder, 2003; Morrison & Meier, 2004; National Guideline Clearinghouse, 2013). Palliative care plans are patient-focused, based on the preferences, values, and needs of the individual and family, and the interdisciplinary team coordinates the care as well as transfers between health care settings (Morrison & Meier, 2004; National Guideline Clearinghouse, 2013).

Ideally, palliative care can be provided throughout the duration of advanced illness, working alongside curative care in a complementary manner [Figure 1]. As the disease progresses, curative care is slowly tapered off and palliative services increase. Once the patient reaches a terminal stage of disease with six months or less to live, he or she is eligible for hospice services, and the patient's family is provided bereavement care after the patient's death (Giovanni, 2012; Morrison & Meier, 2004; National Guideline Clearinghouse, 2013).

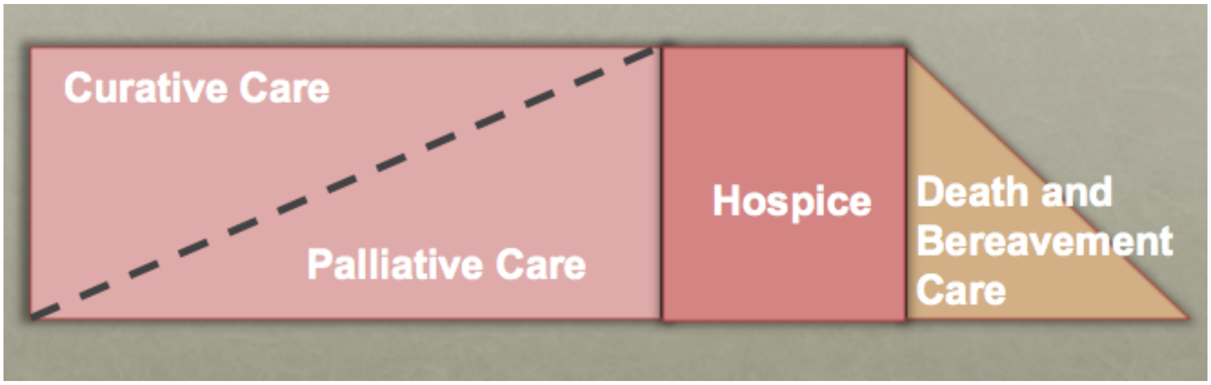

Figure 2.1 Model of the Palliative Care Continuum

Hospice is a well-known model of palliative care, focusing on individuals with terminal conditions at the end of life (S. R. Connor, 2007; Giovanni, 2012). This interdisciplinary model has been shown to improve patient quality of life as well as family member bereavement outcomes (Rickerson, Harrold, Kapo, Carroll, & Casarett, 2005). While some challenges still remain to timely hospice referral, hospice is generally seen by practitioners as a beneficial service for patients nearing the end of life, and referral rates for hospice have improved in recent decades (Iwashyna & Christakis, 1998; National Hospice and Palliative Care Organization, 2013).

Palliative services outside of hospice, however, are lesser known and understood by both patients and health care professionals (Cherny, 2009). Non-terminal palliative care can be offered throughout the continuum of health care settings and in both in-patient and out-patient formats (*Dying in America*, 2014). It is provided as either basic or specialty palliative care [Table 1.]. *Basic palliative care* is most common, delivered by clinicians who do not specialize in palliative care, such as disease-oriented physicians (e.g., neurologists, oncologists, etc.). *Specialty palliative care* is provided by professionals who are certified as palliative care specialists, and it is most commonly offered in an acute hospital-based setting (*Dying in America*, 2014).

Table 2.1 Definitions of Delivery Mechanisms of Palliative Care

Hospice Care	Model of palliative care that provides services in the last six months of life. Usually covered under the Medicare Hospice Benefit.
Basic Palliative Care	Care that is palliative in nature and provided by clinicians who are not palliative care specialists, such as primary care physicians, specialty physicians, and complementary clinicians.
Specialty Palliative Care	Care that is delivered by clinicians who are palliative care specialists, including physicians who are board certified in palliative care as well as palliative-certified nurses, social workers, and chaplains.

(*Dying in America*, 2014)

Currently many non-hospice palliative care programs are offered on a brief, consultative basis, and they do not address patient health issues on a long-term spectrum (Manfredi et al., 2000; Morrison, Augustin, Souvanna, & Meier, 2011; Morrison, Maroney-Galin, Kralovec, & Meier, 2005; Walshe, Todd, Caress, & Chew-Graham, 2009). Recent recommendations, though, assert that palliative services can be effective early in the disease course and should be implemented throughout the spectrum of a chronic illness in conjunction with curative care (Murray, Kendall, Boyd, & Sheikh, 2005; National Guideline Clearinghouse, 2013). Because of this need, the Center for Medicare and Medicaid Services (CMS) is currently pilot testing a program to support long-term palliative care programs throughout the country (Centers for Medicare & Medicaid Serivces, 2014b). The development of these programs is opening the door to the proliferation of new models of palliative care, such as long-term outpatient palliative care.

Outpatient Palliative Care

Outpatient palliative care clinics are becoming more common, and studies are beginning to show the positive effects of these services on chronic disease. These services can be provided either as a one-time consultation or as ongoing care concurrent with curative care. Outpatient palliative services can offer the opportunity to identify and address palliative issues early in the disease course, potentially reducing and avoiding preventable medical crises (Meier & Beresford, 2008).

Chronic disease does not develop in a silo. As individuals age, the likelihood of multiple co-morbid conditions increases (Fried, Ferrucci, Darer, Williamson, & Anderson, 2004). This can place a significant onus on patients and caregivers to manage multiple diseases and their respective treatments. Often the burden of communication between practitioners falls onto the patient and family as well (Norris et al., 2003). Outpatient palliative care teams offer care coordination throughout the duration of these diseases, ensuring that all providers are kept informed, that medications do not interact, and that patients and caregivers' questions are answered promptly (Meier & Beresford, 2008). By integrating palliative services into patient care early in the disease course, the patient and his or her practitioners may be better able to effectively manage the coordinated care of multiple conditions.

Because outpatient palliative care is a relatively new and growing service, the results of only a few studies are available on the topic. In one study, Rabow et al. (2003 & 2004) found that most patients (68.6%) reported that they would have wanted the palliative intervention earlier in their disease (Rabow, Dibble, Pantilat, & McPhee, 2004; Rabow, Schanche, Petersen, Dibble, & McPhee, 2003). Participants (65.7%) appreciated that the comprehensive care team (CCT) team discussed difficult topics with them, such as advance care planning, and 80% of patients reported that the CCT intervention improved their spiritual well-being as well. All participants (100%) reported that they felt “cared for,” “valued,” “listened to,” or that they received “compassionate” treatment from the CCT. Eighty percent of patients reported an increased connection with their primary care physicians, and 71.4% said they felt closer to their caregivers as well (Rabow et al., 2003).

Palliative care has also been shown to improve patient symptoms. In a quantitative portion of the study by Rabow et al (2004), patients with cancer, advanced chronic obstructive pulmonary disease (COPD), or advanced congestive heart failure (CHF) received either a palliative outpatient intervention (CCT) or usual care, depending on which, of two, primary care clinics they attended for care (Rabow et al., 2004). The intervention group had significantly reduced dyspnea, or shortness of breath, compared to the control group, and sleep quality improved for those receiving palliative care as well. Anxiety for the palliative care group decreased significantly from 6 months to a year after the start of the intervention, whereas anxiety worsened in the control group during this time. Spiritual well-being also improved in the palliative care group compared to control patients. In terms of healthcare utilization, control patients made significantly more visits to their primary care physician as well as to urgent care than palliative care patients, indicating that the palliative program may help prevent unnecessary medical events and crises (Rabow et al., 2004).

Follwell et al (2009) conducted a study on the effects of an outpatient palliative care consultation on patients with metastatic cancer recruited on initial referral from a comprehensive cancer center in Toronto, Ontario. Significant improvements were seen for pain, fatigue, nausea, depression, anxiety, drowsiness, appetite, dyspnea, insomnia, and constipation at both one week and four weeks. The consultation also led to improved patient satisfaction, and the results suggest that patients experienced clinically significant improvements from the program (Follwell et al., 2009).

Temel et al (2010) conducted a landmark study where an outpatient palliative care intervention was integrated into cancer care at diagnosis for randomly assigned patients. The study examined the effects of the intervention on health-related quality of life, on mood, and on health care utilization. Patients in the palliative intervention had significantly higher quality of life scores at 12 weeks than the control group, and the proportion of palliative patients with depression at 12 weeks was significantly lower than in the control group. Among those who died during the study, a higher proportion of patients in the control group received aggressive end of life care than those in palliative care. Lastly, and perhaps most interestingly, despite being less likely to receive aggressive end of life care, palliative patients had significantly longer survival times than individuals in the standard care group (11.6 vs. 8.9 months) (Temel et al., 2010).

These studies indicate that outpatient palliative care can provide numerous physical, psychosocial, and spiritual benefits for individuals coping with various chronic illnesses. Although access to outpatient programs is more limited than for acute inpatient programs, this access promises to improve on a regional basis. In Georgia, hospice agency licensure limits care to that provided in the last six months of life, preventing agencies from providing non-terminal palliative care. However, these licensure regulations were rewritten and reapproved in 2015 to allow hospice agencies in Georgia to provide ongoing, in-home palliative care prior to hospice initiation, greatly extending palliative care access throughout the region ("Rules and Regulations for Hospices," 2015). With the impending expansion of palliative care access, it will be crucial to educate staff at these agencies on how the service can specifically benefit different disease populations. Additionally, it will be important to inform providers on the range of palliative services available to their patients. Unfortunately, because of the close relationship between palliative care and hospice, there is often a stigma associated with palliative care, and many of the challenges that have faced hospice referrals, such as knowledge, misperceptions, and communication, are also barriers to palliative care referrals (Fadul et al., 2009). Based on numerous studies, healthcare provider knowledge and attitudes represent the most significant barrier to successful palliative care referrals for patients.

Knowledge and Attitudes

Both patient and physician knowledge and attitudes about palliative care influence referral patterns (Bestall et al., 2004). There is common confusion between hospice and non-hospice palliative care both for practitioners and for patients, and as a result, palliative care is frequently interpreted as being relegated to the end of life or requiring the cessation of curative treatments (*Dying in America*, 2014; Rodriguez, Barnato, & Arnold, 2007). These misperceptions of palliative care as terminal care services can prevent health care professionals from making appropriate referrals and can prevent patients from accepting services they may need (Fadul et al., 2009). Therefore, to best understand potential knowledge and attitudinal barriers to palliative care use, one must consider those challenges facing hospice utilization as well.

Studies have shown that the most common barrier to these programs is misperceptions or knowledge deficits about the purpose of and eligibility requirements for services (Carver et al., 1999; B. Johnson & Slaninka, 1999). Two separate surveys in 2011 and 2012, conducted with healthcare consumers, found respectively that 78% and 83% of Americans do not know what palliative care is [Figure 2] (CAPC (Center to Advance Palliative Care), 2011; CHCF (California HealthCare Foundation), 2012). Because of the serious lapse in consumer understanding of palliative care, it is essential for practitioners, the gatekeepers to these services, to provide accurate information to patients. Unfortunately similar knowledge gaps have been noted in professional populations as well.

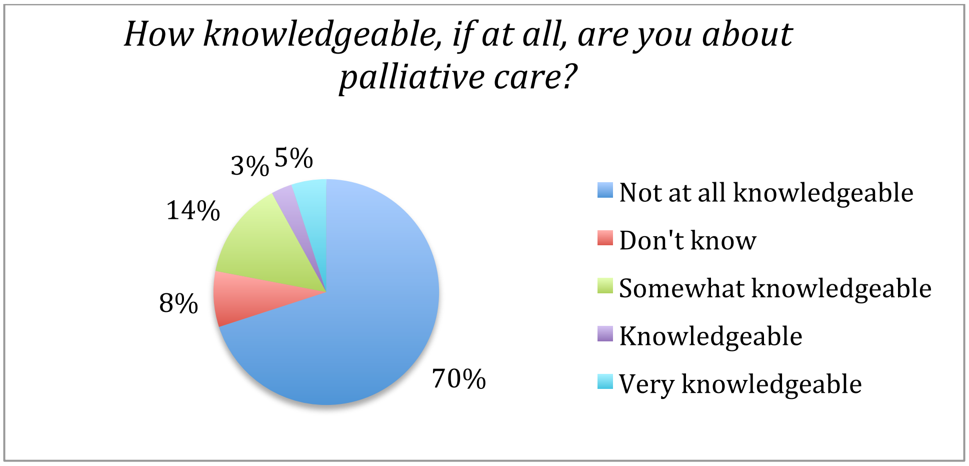

Figure 2.2 Consumer Awareness about Palliative Care (CAPC (Center to Advance Palliative Care), 2011)

Several studies have found that physicians commonly associate palliative care with end of life care, limiting the number of appropriate referrals to the service (Fadul et al., 2009; Rodriguez et al., 2007). In one study, many respondents thought palliative care was equivalent to "pulling the plug," and very few thought palliative care had a role outside of terminal care (Rodriguez et al., 2007). Research has even shown that the term "palliative care" may carry these negative connotations, as a name change to "supportive care" elicited a statistically significant increase in physician referral patterns in one hospital system (Dalal et al., 2011; Fadul et al., 2009). The name change in this study was significantly associated with shorter intervals between patient admission to the cancer clinic and first palliative care consultation (9.2 months vs. 13.2 months), and the time between palliative consultation and death or last follow up was significantly longer as well (6.2 months vs. 4.7 months) (Dalal et al., 2011). These results indicate that perceptions of the name "palliative care" may still be associated with hospice and terminal care, resulting in referrals later in the disease course and shorter time periods on the service prior to death.

A separate study on referral patterns, conducted by Ahluwalia & Fried (2009) examined physicians' reported referrals to outpatient palliative services in comparison to the proportion of their patients who may be eligible for the service. While 70% of physicians reported making palliative care referrals, the median number of referrals was three per physician in the previous year. These referral patterns contrasted with the numbers of eligible patients the physicians saw, as 84.1% reported that over one third of their patients had two or more chronic conditions, indicating palliative care eligibility (Ahluwalia & Fried, 2009). Respondents reported that the most common reason for non-referral was that palliative care was not appropriate for their patients. However, the gap in referral, as evidenced by the study, would indicate that physicians are not fully aware of the eligibility criteria for non-hospice palliative services (Ahluwalia & Fried, 2009).

The available research highlights the deficiencies in physician knowledge pertaining to the distinction between hospice and palliative care as well as their general understanding of patient eligibility for the service. Unfortunately, as physicians generally serve as the gatekeepers to these services, limitations in their understanding will subsequently impact their patients' knowledge and utilization of the services as well. Because different physician specialties will have different experiences with palliative care, it is important to understand knowledge deficits of those physician specialties treating patient populations who are most appropriate for palliative care, such as oncologists and neurologists. Efforts then need to be made to further educate physicians about the distinction between hospice and non-terminal palliative care as well as the utility of these services for their respective patient populations.

Palliative Care and Parkinson’s Disease

In the early development of hospice in the U.S. in the 1970’s and 1980’s, the movement focused primarily on providing services to individuals with cancer; however, over time increasing numbers of non-cancer patients have utilized the service (Centers for Medicare & Medicaid Services, 2009; S. R. Connor, 2007). Non-hospice palliative care is undergoing a similar shift in patient demographics, with a majority of current research currently focusing on cancer and pain patient populations. These studies have recognized the value and benefits of long-term palliative care, and they have begun to focus on integrating palliative care into general disease management (Greer et al., 2012; Smith et al., 2012; Temel et al., 2010). Unfortunately there are many chronic conditions in which palliative care would be beneficial; however, the field has not yet focused on their need (Currow, Agar, Sanderson, & Abernethy, 2008; Morrison & Meier, 2004).

As outpatient palliative care continues to develop and grow, it will be important for services to be examined in the context of other chronic illnesses. Neurodegenerative illnesses, in particular, are often incurable, and treatment has to focus on symptomatic management instead (American Academy of Humanities, 1996; Peter Bede, Dominic Ó Brannagáin, Stefan Lorenzl, David J Oliver, & Orla Hardiman, 2011). While palliative care is now starting to be integrated into patient care earlier in the course of chronic disease, neurodegenerative patients often don’t experience this interdisciplinary palliative care until they are admitted to hospice late in life (American Academy of Humanities, 1996; Kutner, Blake, & Meyer, 2002). Evidence indicates, however, that this palliative care should begin much earlier for those affected by neurodegenerative diseases.

The National Home and Hospice Care Survey has noted that non-cancer diagnoses, and particularly neurologic diagnoses, have been associated with live discharges from hospice care (Kutner et al., 2002). Hospice data provided by the Centers for Medicare and Medicaid Services indicates that the proportion of patients with neurologic conditions (dementia, Alzheimer's disease, and PD) has increased from 16% in 2004 to 19% in 2009, and the average length of stay for these patients is nearly double that of all other diagnoses (101 days vs. 56 days) (Centers for Medicare & Medicaid Services, 2009). These prolonged lengths of stay are due both to the difficulty in prognostic accuracy for neurodegenerative disorders as well as to the fact that interdisciplinary palliative care has been shown to render optimal outcomes for many neurodegenerative patients, potentially postponing death for these patients. This evidence highlights the need to integrate palliative care early in the disease course prior to the end of life (American Academy of Humanities, 1996; Wilcox, 2010). The need for and effects of palliative care also need to be examined for individual neurologic conditions.

PD is the second most common progressive neurodegenerative disease in the U.S. (Grosset, Fernandez, & Okun, 2009). Survival for individuals with PD varies greatly but has been estimated to be an average of 10 to 15 years, depending on age of onset (Wilcox, 2010). PD is chronic, progressive, and incurable (Grosset et al., 2009). Treatment for PD consists of symptomatic management to improve quality of life, and a palliative approach, particularly at the end-of-life, is advocated for best care (Bunting-Perry, 2006; Currow et al., 2008; Giles & Miyasaki, 2009; Hasson et al., 2010; Wilcox, 2010).

Regarding the potential palliative needs of PD patients, approximately 40% of individuals with PD report pain associated with muscle rigidity and cramping, and this is generally managed through a combination of dopaminergic and pain medications, depending on symptoms and frequency (Bunting-Perry, 2006; Wilcox, 2010). Sleep disorders, such as restless leg syndrome, sleep apnea, REM sleep behavior disorder (RBD), are very common in PD, sometimes developing in advance of PD symptoms (Chaudhuri, Healy, & Schapira, 2006). Treatments vary depending on the diagnosis and cause of sleep conditions (Bunting-Perry, 2006). The muscle rigidity of PD also becomes less responsive to medications as the disease develops, and conditions such as dysphagia, or difficulty swallowing, often develop and cause issues such as choking and aspiration (Wilcox, 2010).

Throughout the illness, patients may be affected by various psychosocial problems, which can directly affect health as well. They may require support and assistance in addressing mood concerns, managing family relationships and dynamics, and planning for future finances and care. As with many chronic conditions, advance care-planning discussions are important in early PD to establish the set care preferences of patients. Depression and anxiety are comorbid with PD, with depression presenting in 40-60% of patients (Bunting-Perry, 2006; Wilcox, 2010) and anxiety disorders presenting in 40% of patients (Walsh & Bennett, 2001).

Recent studies recommend extending a palliative approach to PD patients in early stages and throughout the continued course of the illness; however, there are still some gaps in research (Hudson et al., 2006; Wilcox, 2010). One primary issue is that these studies focus on a palliative approach taken directly by neurologists rather than working with outpatient palliative specialty services (Wilcox, 2010). And while neurologists are trained to apply basic palliative principles in their care of PD, they do not always have the resources or expertise to provide the full range of services of an outpatient palliative team (Hudson et al., 2006). Research needs to consider the integration of outpatient palliative care services into the chronic management of PD.

Currently only one movement disorders center has published information on working collaboratively with outpatient palliative care for PD patients (Miyasaki, 2013). The clinic operates in Toronto, Ontario, Canada. While this clinic serves as a potential model of care for neurology and palliative specialty collaboration, the Canadian healthcare system may be more conducive to the development of this integrative system than that of the U.S. The response from healthcare providers in this clinical collaboration has been positive; however, clinical effectiveness of services in this population has not yet been examined (Miyasaki, 2013).

Theory and Use of Non-Terminal Palliative Care

Social Ecological Model

Application of a conceptual model allows for more comprehensive examination of the interplay of factors affecting the use of non-terminal palliative care by PD patients. Proposed and developed by Kenneth McLeroy (1988), and based on an ecological model developed by Urie Bronfenbrenner (1997), the social ecological model for health promotion asserts that behavior both affects and is affected by the social environment. As such, in order to understand and influence behavior, we must understand the social ecological context in which behavior occurs (Bronfenbrenner, 1997; McLeroy et al., 1988). McLeroy describes the ecological system in terms of multiple levels of influence: intrapersonal factors, interpersonal processes and groups, institutional factors, community factors, and public policy (McLeroy et al., 1988). Each factor within these ecological levels influences the others, ultimately impacting individual behavior.

The intrapersonal level refers to the individual characteristics of the person, including knowledge, attitudes, behavior, developmental history, race, sex etc. (McLeroy et al., 1988). The interpersonal level is described by the individual’s network and support system, both formal and informal. This level includes the individual’s family, school, work, and friendship groups (McLeroy et al., 1988). The institutional level of influence consists of forces within the larger social system, such as social institutions and organizations with both formal and informal processes of operation (McLeroy et al., 1988). The community level of influence in this model consists of three specific components: the direct primary groups to which a person belongs, the relationships in organizations and groups in a specific area, and/or a geographically and politically determined region and population. Lastly, the public policy level refers to the local, state, and national laws and policies that may directly or indirectly influence individual behavior as well as the societal norms that influence these policies (McLeroy et al., 1988). Factors at all of these levels affect the use of non-terminal palliative care, and, while this project focuses specifically on influences at the intrapersonal and interpersonal, it has the potential for indirect influence on the other levels of the framework as well [Figure 3].

Within the intrapersonal level, among other influences, factors affecting palliative care use include a person's understanding of his or her disease and prognosis, whether he or she is aware of the availability and purpose of palliative care, and whether he or she has preconceived aversions to palliative care (Cherny, 2009; Dalal et al., 2011; Fadul et al., 2009). As discussed previously, because of the more well-known development of the hospice movement and its historical ties to palliative care, many stigmas regarding the end of life that are placed on hospice are also mistakenly attributed to palliative care (Dalal et al., 2011; Fadul et al., 2009). Therefore, many individuals may be hesitant to use non-terminal palliative care for fear that it is associated with the cessation of curative treatments and relegated to the end of life (Cherny, 2009). The influence of these intrapersonal factors on palliative care use in a PD patient population is relatively unknown. This project aims to explore and enhance understanding of the intrapersonal level of the social ecological model by asking PD patients about their perceptions of and previous experiences with palliative care.

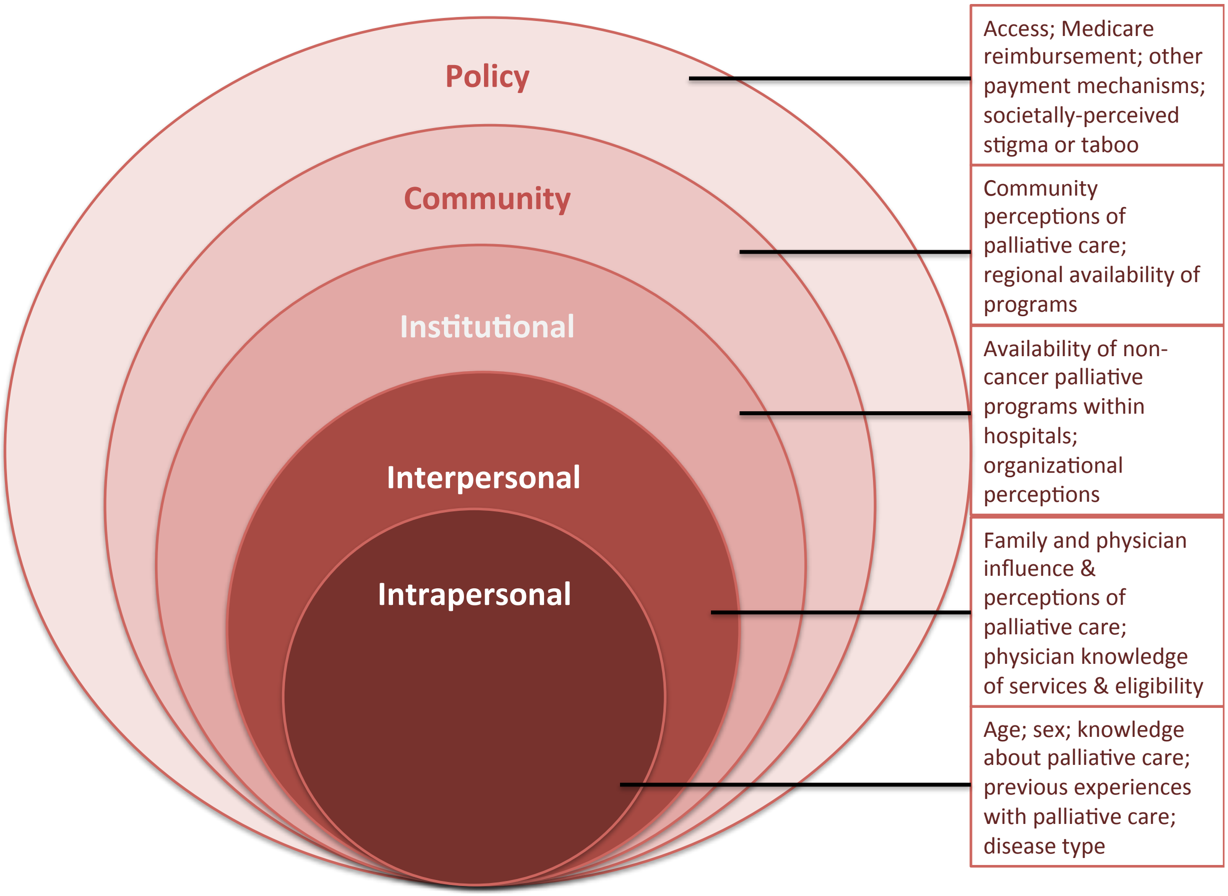

Figure 2.3 A Social Ecological Conceptualization of Palliative Care Usage

Other individual determinants, such as race, may also affect an individual's referral and utilization of palliative care services. Numerous studies show that African Americans are under-served by palliative and hospice care programs; although the actual rate of disparity varies between studies (S. Connor, Elwert, Spence, & Christakis, 2008; Greiner, Perera, & Ahluwalia, 2003). Much of this disparity may result from an interaction between common stigmas associated with palliative and hospice care and cultural and racial differences in perceptions and preferences of end-of-life care. Research has shown that African Americans may have a stronger preference for life-sustaining treatment, reduced comfort in discussing death, a greater distrust in the healthcare system, and spiritual beliefs which may appear to conflict with goals of hospice and palliative care (Crawley et al., 2000; K. S. Johnson, Kuchibhatla, & Tulsky, 2008; Reese, Ahern, Nair, Joleen, & Warren, 1999). These perceptions affecting African American use of palliative care stem from both historical and current events, sociocultural values and religious beliefs, and education about available services within the healthcare system (Crawley et al., 2000). Each of these factors would therefore need to be addressed to ameliorate the racial disparity in service use.

Disease type is another intrapersonal factor that plays a distinct role in the utilization of palliative care services. In the historical development of hospice and palliative care, the service was initially accessed almost exclusively by cancer populations (S. R. Connor, 2007). While hospice first served a population consisting of 90% cancer patients, that proportion has since fallen to 30% in 2010, as physicians began to recognize the benefits of hospice for other disease populations (Aldridge, Canavan, Cherlin, & Bradley, 2015; S. R. Connor, 2007). Non-terminal palliative care is more slowly undergoing this same shift in demographics, but currently programs still most commonly target individuals with cancer (Goldsmith, Dietrich, Du, & Morrison, 2008; Hui et al., 2010). This trend could potentially inhibit the growth of non-terminal palliative care for individuals with PD, as these patients as well as their providers are less likely to understand the benefits of the service for the population (Giles & Miyasaki, 2009). This project aims to examine this factor by measuring the palliative needs of PD patients, as well as by exploring perceptions of that need in direct interviews with patients.

Interpersonal determinants of palliative care use include the influence of family and physicians on patient perceptions of illness and treatment options (McLeroy et al., 1988).

Because of the historical relationship with end-of-life care as well as the fact that palliative care is most often initiated in advanced disease, fears of and discomfort with end-of-life care may have significant influence on palliative case use (Fadul et al., 2009). Research has indicated that patients whose familial and clinical caregivers accept death are more likely to acknowledge the end-of-life process, making them more open to discussing care options like palliative care and hospice in advanced and terminal disease (Prigerson, 1992).

Physician knowledge of palliative care services directly affects patients' use of palliative treatment as well. Several studies have shown that healthcare professionals still commonly misunderstand the purpose and availability of non-terminal palliative care, and this lack of knowledge directly affects palliative care use by patients, who often require information and education on services available to them (Ahluwalia & Fried, 2009; Fadul et al., 2009; Rodriguez et al., 2007). Any intervention to promote palliative care would need to consider physician attitudes and education to sufficiently address their influence in palliative care referral.

A prominent factor in the institutional level affecting palliative care is the availability of palliative care programs for various patient populations (Morrison et al., 2005). Several studies have found that the number of hospital palliative care programs has grown in recent years; however, the prevalence varies drastically by geographic location and by the type and size of hospital (Glass & Burgess, 2011; Goldsmith et al., 2008; Hui et al., 2010; Morrison et al., 2005). One significant factor associated with a hospital having a palliative care program is acting as or having an accredited cancer center on-site (Goldsmith et al., 2008; Hui et al., 2010; Morrison et al., 2005). Similar to the trend of hospice care originally targeting cancer populations, non-terminal palliative care is most often provided to patients with cancer diagnoses (Grande, Farquhar, Barclay, & Todd, 2006; Walshe, Chew-Graham, Todd, & Caress, 2008; Walshe et al., 2009). This is due in part to professional and organizational misperceptions about the utility of palliative care for non-cancer populations (American Academy of Humanities, 1996; *Dying in America*, 2014). The current study aims to address this issue by examining the palliative need of PD patients to better inform palliative clinics on how they can meet the needs of this population.

Because of the rather general definition of "community" in sociological terms, there are many ways in which this factor could be contextualized in terms of palliative care utilization (McLeroy et al., 1988). It could refer to the general exposure to, and sentiments of, the community/neighborhood towards palliative care, as negative community network perceptions of the service could influence an individual's comfort with palliative treatment. The community level of influence could also describe physician and clinic relationships with palliative care clinics and their willingness to refer to such services (*Dying in America*, 2014). As these ecological levels influence one another, the interpersonal factors affecting physician referral could also affect the collaboration between clinics at the community level. This project may have a potential impact on the community level through two mechanisms. First, the project aims to understand the palliative needs of PD patients, and this information may be used to increase clinician and patient awareness of the appropriateness of the service for the population. Second, it aims to examine the referral patterns of physicians regarding palliative care for PD patients. By understanding the factors that influence physician referrals, these factors can potentially be manipulated to increase non-terminal palliative care referrals for the population.

Factors in the public policy level of the social ecological model affecting access to palliative care include hospital funding for services and political and financial incentive to provide services. Based on requirements of the Medicare Hospice Benefit, if, while on hospice, an individual's health plateaus or improves so that they no longer meet terminal eligibility, that individual is discharged live from hospice (Centers for Medicare & Medicaid Serivces, 2014a). The National Home and Hospice Care survey has reported that individuals who are discharged alive from hospice are more likely to have neurologic diagnoses, such as PD (Kutner et al., 2002). While this indicates that palliative care has positive effects on neurologic populations in particular, it highlights a need for palliative services prior to hospice for PD patients. Unfortunately, without a formal funding mechanism through Medicare, palliative clinics are required to charge separately for the individual interdisciplinary services provided rather than through one solid charge like with the Medicare Hospice Benefit (Centers for Medicare & Medicaid Serivces, 2014b). This project can potentially inform public policy by demonstrating the appropriateness of non-terminal palliative care for PD patients, highlighting the need for a payment mechanism to be developed.

Also at this level of influence, sociocultural beliefs regarding palliative, end-of-life, and curative care play a direct role in palliative service use. Traditionally, the U.S. healthcare system has reflected a dichotomy of beliefs regarding the provision of curative vs. palliative care. Each service has historically been offered at the exclusion of the other, and these beliefs about the services have affected the type of care provided to patients managing chronic disease and those nearing the end of life (Morrison & Meier, 2004). Additionally, the societal taboo surrounding death and dying tends to lead to a general avoidance of end-of-life discussions as well as of any service considered to be affiliated with the end-of-life (Cherny, 2009; Kaufman, 2005). As a result of the association between hospice and non-terminal palliative care, this stigma regarding end-of-life extends to perceptions of palliative care as well (Cherny, 2009). These societal beliefs affect policymakers at the macro-level who may control funding to palliative programs, as well as patients, family members, and physicians at the interpersonal level who make direct decisions concerning whether or not to access palliative care. By adding to the literature on non-terminal palliative care, this project will help increase awareness of these services, thus helping to dispel patient, practitioner, and societal misperceptions regarding palliative care.

Social Exchange Theory

One significant factor at the interpersonal and community levels of the social ecological model that must be considered is the physician referral process. Physicians typically serve as the "gatekeepers" to various treatments, therapies, and other services available to patients. Without information or education on the availability of such services, and without a referral from the physician, many patients remain unaware of the programs that may positively affect the quality of their care and their quality of life. This referral process is particularly important for PD patients who require treatment from multiple clinicians for the best outcomes in care (Prizer & Browner, 2012). Unfortunately, relatively scant research has examined the determinants behind physician referral patterns. A few studies, however, have used tenets from the Social Exchange Theory (SET) to provide a theoretical and conceptual basis for examining and understanding the physician referral process (Shortell, 1974; Shortell & Anderson, 1971).

SET is a value expectancy theory, which indicates that it involves a balance between individual expectations regarding the outcomes of performing an action as well as their subjective values or rewards about those outcomes (Sutton, 1987). SET proposes that individuals are motivated to interact with another person in a specific activity if they expect a positive outcome from the interchange. If the benefits of the outcome are more rewarding than the cost of the activity, the relationship will be valued and the individual will be more likely to engage in the collaborative behavior again in the future (Shortell, 1974).

With regard to SET and the current project, physicians may be expected to refer patients to palliative care if they believe the specific rewards from the referral will outweigh any costs. Potential rewards from such a referral could include better-managed patient symptoms and quality of life, fewer complications in patient care, better patient care coordination between multiple practitioners, and greater patient and family satisfaction in overall care. The potential costs of the referral could include a loss in physician autonomy over patient care or additional patient complications resulting from the additional care consultations. SET is used in this study to demonstrate to physicians the many potential beneficial outcomes to palliative referrals for PD patients that may outweigh the costs of such a referral. Aim 3 in this study entails the examination of the constructs of the perceived costs and rewards of neurology staff in providing a referral for outpatient palliative care for PD patients.

Through the application of the social ecological framework and social exchange theory, the factors influencing non-terminal palliative care use for PD patients will be better understood. This understanding will potentially reveal insights into the ways in which health professionals can increase the use of non-terminal palliative services in this population.

Chapter Conclusion

Although palliative care has been a well-known clinical approach since the hospice model was brought from England in 1973, non-hospice palliative care has only emerged as a specialty in the last two decades (S. R. Connor, 2007). Because of this close relationship to hospice care, palliative care faces many similar barriers in development, and scant research has been conducted on non-hospice palliative care alone (Billings, 1998).

Palliative care can be particularly beneficial for PD treatment, because of its incurable nature, long duration, and complex and interdisciplinary treatment needs (American Academy of

Humanities, 1996; Hudson et al., 2006; Prizer & Browner, 2012). While several studies have indicated that PD patients have palliative needs, those needs that are unmet by standard neurology care have not been identified (Bunting-Perry, 2006; Ghoche, 2012; Hudson et al., 2006). This study will address this gap by identifying the palliative needs of PD patients that are currently unmet by standard neurology care. Additionally, this study will examine factors affecting palliative care referral and use present in the five social ecological levels of health behavior.

As gatekeepers to supplementary services, such as palliative care, physicians are responsible for educating patients about care options and providing referrals to access these services. Relatively little is known, though, in terms of the physician referral process. Researchers have previously examined the determinants of physician referrals for one-time consultative purposes using constructs from SET. However, this theoretical approach has not been utilized to understand the costs and rewards of referrals to ongoing collaborative treatments for patients. This project aims to address this gap by exploring the perceived costs and rewards of physicians referring to outpatient palliative care services. The information that will be drawn from the completion of this project will provide knowledge to facilitate integration of neurology as well as outpatient palliative treatment early in the course of PD.

The purpose of this study is to understand the palliative need of PD patients, as well as the individual-, interpersonal-, institutional-, community-, and policy-based barriers and aspects of quality care in the population. This will be achieved through the implementation of three aims. Aim 1 will examine the unmet palliative need of PD patients as reported by patients and neurologists, and it will explore the extent to which PD patients and neurologists agree on the unmet palliative needs of PD patients. It is hypothesized that non-physical need categories will have more unmet need than the physical need category, and that PD patients and neurologists will not agree on the unmet palliative needs of PD patients. PD patients will report greater unmet need. This aim will also focus on understanding how unmet palliative needs affect PD patient quality of life. It is hypothesized that these unmet needs negatively impact PD patient quality of life. To address Aim 2, qualitative methods will be used to explore patient experiences of palliative need. This aim will focus on patient experiences and perceptions of symptoms and palliative need. This aim will be guided by the following research questions: How do physical, psychological, social, financial, and spiritual needs affect PD patient quality of life? How do different levels of the social ecological framework shape perceptions of and access to palliative care services? Aim 3 will examine the costs and benefits to physicians of referring PD patients to palliative care using Social Exchange Theory. It is hypothesized that neurologists perceive more costs than benefits to palliative referrals, and that these perceived costs negatively affect palliative care referrals. Through the completion of these three aims, this project will provide a more in-depth understanding of the unmet palliative needs of PD patients as well as the barriers and facilitators to the use of palliative services by this patient population.

CHAPTER 3

METHODOLOGY

Approach

Over the past few decades, mixed methods research has emerged as a technique to examine problems or phenomena from several angles, utilizing at least one quantitative method and one qualitative method (Creswell & Plano Clark, 2011; C Teddlie & Tashakkori, 2003). Mixed methods research is most appropriately employed in examining research questions that warrant contextual examination from multiple perspectives, providing a more thorough and complete picture of the problem. In exploratory studies, such as this one, a mixed methods approach allows the researcher to gain insight into the individual factors influencing quantitative responses through in-depth qualitative interviews with participants. This information is valuable in guiding the researcher in the development of future projects to better understand the phenomena under study. In using both qualitative and quantitative techniques, the researcher aims to draw from the strengths of each methodology with the goal of providing the most comprehensive answer to the issue under study (Creswell, Klassen, Plano Clark, & Smith, 2011; Luyt, 2012).

Design

Mixed method design typology has undergone significant discussion and debate, and different scholars promote differing criteria for categorizing mixed methods research into typologies (C Teddlie & Tashakkori, 2003). Many scholars agree, though, that, among other components, the development of a design typology should consider the number of methods used, the number of phases in the study, the type of implementation process, the stage of integration, the priority of methodology, the functions of the research study, and the theoretical perspective (Maxwell & Loomis, 2003; C Teddlie & Tashakkori, 2003; Charles Teddlie & Tasshakori, 2006). This study was guided by one of the prototypical mixed methods designs: the explanatory sequential design (Creswell & Plano Clark, 2011; Zhang & Watanabe-Galloway, 2013).

In sequential mixed methods designs, quantitative and qualitative datasets are collected in a specific order to allow the results of one method to inform the next method (Doyle, Brady, & Byrne, 2009; Zhang & Watanabe-Galloway, 2013). The explanatory sequential design begins with a quantitative phase of data collection followed by a qualitative phase during which the researchers aim to learn more about the initial quantitative results (Creswell & Plano Clark, 2011; Doyle et al., 2009; Fetters, Curry, & Creswell, 2013). The primary purpose of this design is to expand upon and better understand initial quantitative results by using a qualitative phase; it is particularly useful in understanding the mechanisms behind different trends in the data (Creswell & Plano Clark, 2011).

A sequential mixed methods design was most appropriate for the current study because the utilization of both quantitative and qualitative methods will allow for a more comprehensive understanding of PD patient needs as well as their understandings of palliative care. The initial quantitative component of the study functioned as a guide for the qualitative piece. Then the qualitative interviews provided additional context and detail to allow for greater understanding of the survey results. In the present study, patients who completed the quantitative survey had the option of providing their contact information to be contacted for the qualitative interview, and all qualitative participants were recruited in this sequential manner. While qualitative interviews were informed by some of the answers on the quantitative surveys, the topics covered in the qualitative interviews were semi-structured. The proposed project was conducted over the course of approximately one year [Table 3.2].

Table 3.1 Project Methodology by Aim and Sample

	PATIENT SAMPLE	NEUROLOGY STAFF SAMPLE
AIM 1	Quantitative Survey: On current palliative needs. Parkinson's Disease Questionnaire – 39: On PD symptoms and quality of life.	Quantitative Survey: On the palliative needs most difficult to address in practice.
AIM 2	Qualitative Interviews: On patients' experiences in the health system as well as on their experiences of palliative need.	
AIM 3		Quantitative Survey: On the perceived costs and benefits to palliative care referrals for PD patients.

Table 3.2 Project Timeline

	2/15	3/15	4/15	5/15	6/15	7/15	8/15	9/15	10/15	11/15	12/15
IRB	X	X									
Aim 1											
Recruitment			X	X	X						
Enrollment			X	X	X						
Quant Survey Administration			X	X	X	X	X				
PDQ-39 Administration			X	X	X	X	X				
Analysis						X	X	X	X		
Aim 2											
Recruitment				X	X	X					
Enrollment				X	X	X					
Qualitative Interviews				X	X	X	X	X			
Transcription					X	X	X	X	X	X	
Analysis								X	X	X	X
Aim 3											
Recruitment			X	X	X	X	X	X	X		
Enrollment			X	X	X	X	X	X	X		
Quant Survey Administration			X	X	X	X	X	X	X		
Analysis						X	X	X	X	X	X
Writing							X	X	X	X	X

Patient Sample

Sampling, Recruitment, and Enrollment

Because individuals with PD compose a relatively minute portion of the overall population (0.2% in 2010) (Kowal et al., 2013; United States Census Bureau, 2010), a purposeful sample of PD patients was sampled for this study (Onwuegbuzie & Collins, 2007). Sample size for the quantitative component of the study was calculated using G*Power 3.1 software (Faul, Erdfelder, Buchner, & Lang, 2009; Faul, Erdfelder, Lang, & Buchner, 2007). To detect a small effect size of 0.20 between the five symptom groups with an alpha of 0.05 and a power of 0.80, a sample of 50 PD patients was needed for the study (Faul et al., 2009; Faul et al., 2007; Peto, Jenkinson, & Fitzpatrick, 2001). To compensate for potential loss and missing data, 60 participants were recruited for the project. Based on recommendations in the literature regarding sample size and reaching saturation in qualitative research using thematic analysis, a recruitment goal of between 20 and 30 patients was established, and ultimately 23 were recruited and interviewed (Braun & Clarke, 2013; Onwuegbuzie & Collins, 2007).

Individuals with PD, for both the quantitative and qualitative components of the project, were recruited through the American Parkinson Disease Association Georgia Chapter support group network as well as through contacts in current professional networks. The opportunity to participate was presented electronically to support groups throughout Georgia and in neurology practices throughout the state. The quantitative survey and PDQ-39 were accessible via a URL link. As these anonymous surveys presented no more than minimal risk, the IRB waived written consent for the quantitative arm of the project (Office of the Vice President for Research, 2014). Eligibility criteria for both participants of the quantitative survey and qualitative interview was: at least 18 years old, a diagnosis of PD, and fluent in English.

For the qualitative interview in Aim 2, a purposive sample of individuals of varying ages, races, and durations of disease was targeted for inclusion in the study in order to elicit a more comprehensive understanding of palliative symptoms and experiences from a variety of perspectives. The interview opportunity was presented to participants completing the quantitative survey in the final question/comment section of the survey. Participants had an opportunity to provide their contact information if they were interested in being contacted for an interview. From this pool of interested participants, a sample of 23 individuals, representative of the general demographics of PD patients, was contacted to schedule a date in which consent was provided and the interview was conducted [Table 3.3] (Willis, Evanoff, Lian, Criswell, & Racette, 2010).

Table 3.3 Qualitative Interview Enrollment

Ethnic and Racial Categories	Females	Males	Total
American Indian/Alaska Native	0	0	0
Asian	0	0	0
Native Hawaiian or Other Pacific Islander	0	0	0
Black or African American	1	0	1
Hispanic	0	0	0
White	9	13	22
Racial Categories: Total of All Subjects	10	13	23

(Willis et al., 2010)

Capacity to consent was determined by the completion of a capacity to consent form following review of the general consent form [Appendix A]. After reviewing the consent form, open-ended questions were asked to determine participant comprehension. For example, “Can you tell me what will happen if you agree to take part in this study?” These questions were used to determine that the participant had the ability to communicate a yes or no decision and that he or she had the ability to understand relevant information. No participants were excluded due to this screening.

Neurologist Sample

Sampling, Recruitment. And Enrollment

For this project, neurologists were quantitatively surveyed on 1) the most difficult palliative needs for neurology staff to assess in practice, and 2) the perceived costs and rewards of referring PD patients to outpatient palliative care. The population surveyed in this portion of the project consisted of neurologists. Because of the relatively rare nature of this healthcare specialty, these professionals were most easily located through convenience sampling of professional organizations supporting movement disorders specialists.

For Aim 1, to detect a small effect size of 0.20 between the five symptom groups with an alpha of 0.05 and a power of 0.80, a sample of 50 neurologists was needed for the study (Faul et al., 2009; Faul et al., 2007). A separate calculation was done for the analysis in Aim 3. For a two-tailed test, assuming a constant of 1.16, an R^2 of 0.20, and a power of 0.80, a sample of 60 neurologists was needed. An enrollment goal of 65 was set to account for missing data (Faul et al., 2009; Faul et al., 2007; Shortell, 1974). To recruit neurologists, electronic surveys were disseminated amongst centers in the National Parkinson Foundation network of professionals. The National Parkinson Foundation network includes specialized clinical experts in the field of PD care, who have the training and experience to comment on the palliative needs of PD patients. The Medical Association of Georgia, a statewide physician advocacy group with 7,800 members, also agreed to share survey information with their members electronically. Neurology and Movement Disorders Centers within Georgia, as identified through the American Academy of Neurology's public directory, were also approached for inclusion in the survey via in-person meetings and email requests. Eligibility for this survey included being over the age of 18, providing consent, and being currently employed as a neurologist. Participants self-selected into the study.

All surveys were delivered through email anonymously via URL link. As this anonymous survey presents no more than minimal risk and signed written consent would be the only record linking the subject to the research, the IRB waived written consent for the quantitative arm of the project (Office of the Vice President for Research, 2014).

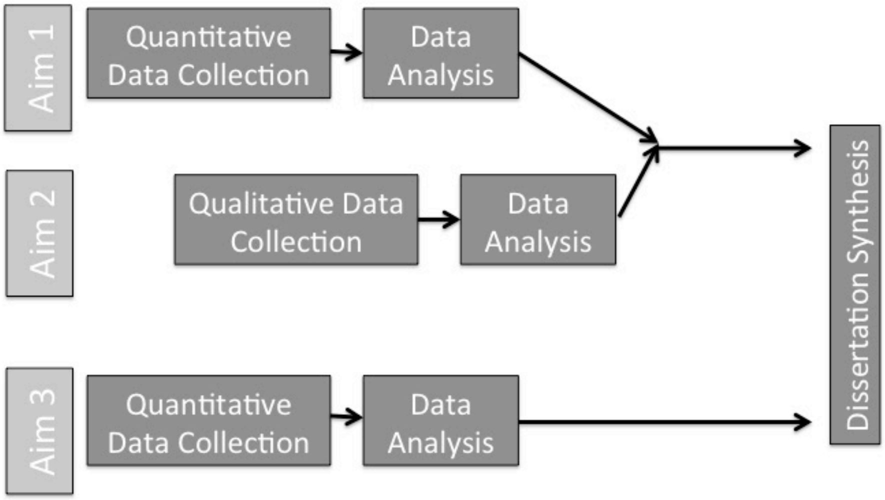

Figure 3.1 Study Design

Aim 1

The purpose of this aim was to determine the unmet palliative needs of PD patients as reported by patients and physicians, and to explore the extent to which PD patients and neurologists agree on the unmet palliative needs of PD patients. Hypothesis A asserted that non-physical need categories, psychological and social needs in particular, will have more unmet need than the physical need category, and hypothesis B asserted that patients will report more unmet need than physicians.

Measures and Data Collection

As part of the quantitative component of the study, participants with PD completed a survey of unmet palliative need based on symptoms outlined in the 12-item Palliative care Outcome Scale, which is a validated instrument used to measure patients' physical symptoms, psychological, emotional, spiritual, and support needs [Appendix B] (Hearn & Higginson, 1999). In this survey, palliative needs, categorized into five domains (physical, psychological, social, financial, and spiritual), were assessed to identify unmet palliative care needs via a 5-point Likert scale (with anchors Very Well to Poorly). Patients were also asked to indicate whether treatment for each symptom was provided by a primary care physician, a general neurologist, a movement disorders specialist, or none of the listed specialists. This allowed for a more comprehensive understanding of which professionals currently work to address which symptoms and how well they are able to treat palliative need.

Prior to use, the content validity of the measure was assessed by a panel of experts on palliative care:

1. **Anne Glass, PhD** – Associate Director of the UGA Institute of Gerontology
   Dr. Glass has conducted research and published numerous manuscripts on palliative care, examining the prevalence of palliative care organizations in Georgia and publishing a report on the state of end-of-life and palliative care in Georgia. She organized a statewide conference on Improving Palliative and End-of-Life Care for Frail Older Adults, sponsored by the Georgia Geriatric Education Center.
2. **Molly Perkins, PhD** – Assistant Professor in the Department of Medicine, Division of Geriatric Medicine and Gerontology at Emory University
   Dr. Perkins has extensive experience in aging and health research, including several studies on end of life and palliative care. She served as a co-investigator on a Templeton Research – funded project to examine chaplain impact on health decision-making in a palliative population, and her other research as a co-

investigator includes funding from NIH/NIA (http://grantome.com/grant/NIH/R01-AG044368-02), the Patient-Centered Outcome Research Institute (PCORI), the Veterans Health Administration (VHA) Office of Rural Health (ORH), and the John A. Hartford Foundation.

3. **Janis Miyasaki, MD** – Associate Professor in the Division of Neurology at the University of Alberta

   Dr. Miyasaki is an expert in the field of palliative care for individuals with PD. She has conducted extensive research in and has numerous publications on the use of palliative care services for PD patients. She also developed the first palliative care program in PD in the world.

4. **Tammie Quest, MD** – Director of the Emory Palliative Care Center

   Dr. Quest is a board certified physician in Hospice and Palliative Medicine, and she serves as the Chief of the Section of Palliative Medicine at the Atlanta VA Medical Center. She leads numerous research projects on palliative care. She is a member of the National Priorities Partnership's Palliative and End of Life Care work group.

5. **Charlene Bunts, MS** – Director of the Georgia Hospice and Palliative Care Organization

   Ms. Bunts has over 30 years in the healthcare industry, specializing since 1996 in hospice and palliative care leadership and management. She has worked in the field both as a nurse clinician and as an administrator.

This panel of experts rated each survey item as either "essential" or "not necessary". The number of essential ratings for each item was tallied. Where N equals the total number of experts and E equals the number who rated the item as essential, the content validity ratio = [(E-(N/2))/(N/2)]. The closer an item is rated to 1, the more essential it is to the survey. Items were automatically retained if they receive a rating of 0.6 or above; items with a rating below 0.6 were considered on a case-by-case basis, dependent upon evidence in the literature supporting or opposing their inclusion.

As a part of this aim, physicians also received a survey consisting of a list of PD symptoms and issues drawn from relevant literature as well as the Palliative Outcome Scale for PD and categorized under palliative care guidelines as described by the Palliative Outcome Scale for PD: 1) physical; 2) psychological; 3) social; 4) financial; and 5) spiritual [Appendix C] (Hearn & Higginson, 1999). Physicians were also asked via a Likert scale to indicate how well they feel they are managing each palliative need for a majority of their patients [Appendix C]. The clinician survey as delivered via emailed web link and was completed online anonymously.

Prior to use, the content validity of the measure for physicians was also assessed by a panel of experts [listed previously] on palliative care. This panel of experts rated each survey item as either “essential” or “not necessary”. The number of essential ratings for each item was tallied. Where N equals the total number of experts and E equals the number who rated the item as essential, the content validity ratio = [(E-(N/2))/(N/2)]. The closer an item is rated to 1, the more essential it is to the survey. Items were automatically retained if they receive a rating of 0.6 or above; items with a rating below 0.6 were considered on a case-by-case basis, dependent upon evidence in the literature supporting or opposing their inclusion.

Table 3.4 Aim 1 Measures and Variables

Measure	Variables
Patient Survey	Physical Palliative Need Psychological Palliative Need Social Palliative Need Financial Palliative Need Spiritual Palliative Need Sex Age Race Socioeconomic Status Duration of PD Complementary Clinician Treatment Non-terminal Palliative Care Treatment
PDQ-39	Mobility Activities of Daily Living Emotional Well-Being Stigma Social Support Cognition Communication Bodily Discomfort
Physician Survey	Physical Palliative Need Psychological Palliative Need Social Palliative Need Financial Palliative Need Spiritual Palliative Need

Data Analysis

SAS v. 9.3, (Cary, NC) was used for the analyses of quantitative variables. The reliability of the instrument was tested using Cronbach's alpha. Based on the content validity, alphas were run for each need domain with and without items deemed unnecessary. Alphas did not improve with the removal of any items, so all were retained. In the patient measure, Cronbach's alphas were calculated for all symptom categories with more than one item (Physical α= 0.88, Psychological α = 0.93, Social α = 0.94, and Financial α = 0.88), indicating good to excellent reliability of the items in the measure. Cronbach's alphas were also calculated for these categories in the physician measure (Physical α = 0.89, Psychological α = 0.84, Social α = 0.85, and Financial α = 0.67). The alpha for the financial category of items was slightly below the threshold for an acceptable value. However, since the consistency was good in the patient survey and removal of any items did not improve upon the reliability, all items in the category were retained for analysis.

Means and standard deviations for each category of need were calculated to determine the extent to which each category is addressed or unaddressed by current care. Higher scores indicated greater unmet need for each symptom. Descriptive statistics for each category were run by treating clinician type, duration of PD, number of complementary therapies used, and use of palliative services to examine the descriptive make up of the participant sample. To examine whether unmet needs varied by physician type, response categories for the degree of need were collapsed into "addressed" and "unaddressed" categories. Chi-square tests were run in each symptom group to examine the proportion of met vs. unmet need.

To test the hypotheses, a MANOVA analysis was run to assess differences in reported palliative need between patients and physicians. This analysis allowed for the comparison of the palliative need reported by patients and reported by physicians.

Sub-aim 1 The purpose of this aim is to understand how unmet palliative needs affect PD patient quality of life. It was hypothesized that these unmet needs negatively impact PD patient quality of life.

Sub-aim 1 measures and data collection For Sub-Aim 1, participants also completed the PDQ-39, which is the most commonly used health-related quality of life measure for individuals with PD [Appendix C] (Bushnell & Martin, 1999). Subscales are assessed via a 5-point Likert scale (with anchors of Never and Always) include mobility (10 items), activities of daily living (6 items), emotional well-being (6 items), stigma (4 items), social support (3 items), cognition (4 items), communication (3 items), bodily discomfort (3 items). Covariates included: age, sex, duration of PD, and number of complementary therapies used. Research examining the validity and reliability of the scale have found acceptable internal consistency for different domains (Cronbach's α= 0.51 to 0.96) and acceptable test-retest reliability (from 0.86 to 0.96, p<0.001) (Bushnell & Martin, 1999). Additionally, the questionnaire is straightforward and quick and should take no more than five to ten minutes for participants to complete. As an instrument used widely in palliative care practice and research, the PDQ-39 complemented the qualitative survey by providing a thorough quantitative assessment of palliative need and quality of life.

Sub-aim 1 data analysis In this aim, the PDQ-39 was administered to examine how symptoms impact patient quality of life. The PDQ Summary Index Score served as the dependent variable, and palliative symptom categories served as the independent variables. For each of the eight dimensions, dimensions scores were calculated by summing the scores of each item in a given dimension and dividing that figure by the maximum possible score for that dimension, multiplied by 100. The Summary Index Score was then calculated by summing the total scores for each dimension and dividing by eight. Lower scores reflected better quality of life.

A multiple regression analysis was run to determine the relationship between patient-reported unmet palliative need and patient quality of life. In this regression, the PDQ index score served as the dependent variable, and the palliative symptom categories from the factor analysis served as the independent variables. Covariates selected for initial analysis included: sex, age, duration of PD, nurse treatment, social work treatment, physical therapist treatment, occupational therapist treatment, speech-language pathologist treatment, and chaplain treatment. Previous research has indicated that PD incidence and symptom intensity may vary based on these factors (De Lau et al., 2004; Lang & Lozano, 1998; Prizer & Browner, 2012). Covariates for a final reduced model were chosen through a backward selection process whereby variables with an $\alpha \geq 0.05$ were systematically removed from the model one by one until all remaining variables were significant.

Aim 2

The purpose of this aim is to understand PD patients' knowledge, awareness, and perceptions of palliative need. This aim focused on patient experiences and perceptions of symptoms and palliative need. This aim also examined barriers and facilitators to palliative care use at the individual-, interpersonal-, institutional-, community-, and policy-levels of the social ecological framework. This aim was explored through qualitative interviews with PD patients using thematic analysis (Braun & Clarke, 2006; Fereday & Muir-Cochrane, 2006).

Measures and Data Collection

The qualitative component of the project involved in-depth interviews with PD patients, focusing on patients' experiences with PD symptoms and clinical interactions with their physicians. Additionally, in these semi-structured interviews, patients described the need for palliative care throughout the course of PD, and they commented on which needs were addressed or unaddressed by their neurology clinics. These interviews explored the various barriers and facilitators to timely and quality non-terminal palliative care throughout the social ecological framework from the perspective of PD patients.

A semi-structured interview guide was developed based on domains included in the Needs at the End-of-Life Screening Tool (NEST) (Emanuel, Alpert, & Emanuel, 2001) and the PDQ-39 (Bushnell & Martin, 1999) with input from dissertation committee members and advisors on appropriate expansion of the tool into an interview guide [Appendix D]. The NEST is a measure commonly used in palliative care to examine the subjective experiences of patients through multiple dimensions (Emanuel et al., 2001). By using this measure as a model for qualitative interview questions, potential palliative needs could be explored in depth with this patient population. The use of the PDQ-39, discussed in more detail in the previous section, allowed for exploration and understanding of patient experiences of quality of life in PD and how it relates to palliative need. The interview guide was also expanded to consider factors throughout all levels of the social ecological framework that may affect palliative referrals.

Interviews were conducted in private locations convenient to each participant and according to availability in the participant's schedule. With the participant's permission, interviews were digitally recorded and transcribed verbatim. Interview participants were assigned a coded identifier to ensure interview transcripts were not directly linked to their personal information. A master sheet of this coding scheme was kept separately from the interview information on an encrypted and password protected USB drive.

Table 3.5 Aim 2 Measures and Variables

Measure	Variables
Patient Interview	Background Diagnosis of PD Current PD Symptoms Palliative Care Understanding Sex Hispanic or Latino origin Race Age Marital Status Education Community Access to Care Employment Annual Income Religious Affiliation

Data Analysis

A codebook of pre-set codes was developed prior to data collection, to assist with tagging, sorting, and organizing data for higher-level analysis [Appendix D]. A priori codes were based on the conceptual framework, research questions, and study aims. Proposed code categories included background, social support, experiences at the PD diagnosis, unmet needs, various symptoms, and access to care. As analysis progressed, emergent codes were added to the codebook. Lindsay Prizer coded all transcripts, and the NVIVO 10 software package was used for data management and to facilitate analysis. This program has the capability to link qualitative textual data with quantitative data stored in SPSS or Excel, making it particularly useful in mixed methods research.

Thematic analysis was used to identify patterns and recurrent themes in the data (Braun & Clarke, 2006; Fereday & Muir-Cochrane, 2006). It adopted an inductive and deductive approach (Fereday & Muir-Cochrane), where initial codes were developed based on previously established palliative care domains (e.g., Emanuel et al., 2001) and other literature used to inform the aims (add some citations here). Consistent with guidelines established by Braun & Clarke, 2006, analysis involved six recursive phases: 1) immersion in the data through repeated rereading of interview transcripts; 2) refinement of the initial codebook; 3) searching for themes among and across codes; 4) reviewing themes and linking these with relevant themes in the literature; 5) refining and naming the final overarching and secondary themes; and 6) writing the results. Analysis was considered complete when themes were refined and fully developed, and when no new themes or relevant data was identified in the interview transcripts.

Aim 3

The purpose of this aim is to examine the costs and benefits to physicians of referring PD patients to palliative care using Social Exchange Theory. It was hypothesized that neurologists perceive more costs than benefits to palliative referrals, limiting potential referrals to PD patients. It was also hypothesized that endorsed costs negatively affect palliative care referrals.

Measures and Data Collection

In the same survey described in Aim 1, physician beliefs regarding the barriers and facilitators to palliative referral were measured via short-answer questions using a four-point Likert scale (with anchors 0-*strongly disagree* to 4-*strongly agree)*. Statements of potential costs and benefits were drawn from previous SET literature on physician referral patterns (Shortell, 1974; Shortell & Anderson, 1971). These items were used to guide the resulting model in order to have the greatest positive potential impact on physician referrals to palliative care for PD patients. The clinician survey was delivered via emailed web link and was completed online anonymously.

Table 3.6 Aim 3 Measures and Variables

Measure	Variables
Physician Survey	Age
	Sex
	Physician Type
	Years in Practice
	Years working with PD patients
	Previous Referral to Non-terminal Palliative Care
	Number of Patients Referred to Non-terminal Palliative Care
	Previous Referral to Hospice
	Number of Patients Referred to Hospice
	Previous Referral to Interdisciplinary Care
	Number of Patients Referred to Interdisciplinary Care
	Complementary Clinicians in Practice
	Level of Agreement with Palliative Care Referrals

Data Analysis

SAS v. 9.3 (Cary, NC) was used to test the reliability of the physician survey instrument using Cronbach's alpha. Means and standard deviations for the pro statements and for con statements were run. After data collection, the Cronbach's alpha was calculated for pro and con item groups. The alpha for the rewards category was good at 0.84; however, the alpha for the costs group of items was .37. Removal of any cost items did not improve reliability. Pearson correlation coefficients and separate Kruskall-Wallis tests were run between each individual SET item and the independent variables and covariates to determine which, if any, cost items did impact palliative referrals. Individually, many of the cost items were endorsed by physicians and were also associated with referral practices, so a decision was made to retain all items in the cost group. A paired t-test was run to determine whether the mean pro and con scores for physicians were significantly different.

To determine whether these perceived barriers and facilitators potentially limit palliative care referrals, a Poisson regression was run with the number of non-terminal palliative care referrals as the dependent variable and means of the pro and con statements as the independent variables. This analysis was most appropriate because the data are count data, where zero was a common value and the data were not be normally distributed. Covariates included in the initial model included: physician type, sex, years in practice, years working with PD patients, and the number of complementary clinicians in practice. Previous research on physician factors that influence care has indicated that physician type, sex, and years in practice may impact palliative and end-of-life care referrals (Ahluwalia & Fried, 2009; Carver et al., 1999; Dalal et al., 2011). As the clinical influence of complementary clinicians addresses additional PD symptoms, access to these clinicians reduce the need for a palliative interdisciplinary team and subsequently affect referrals (Prizer & Browner, 2012). Covariates for a final reduced model were chosen through a backward selection process whereby variables with an $\alpha \geq 0.05$ were systematically removed from the model one by one until all remaining variables were significant.

CHAPTER 4

THE LONG-TERM PALLIATIVE NEEDS OF PARKINSON'S DISEASE PATIENTS: A MIXED METHODS STUDY

RESULTS[1]

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[1] Prizer, L.P., Gay, J.L., Perkins, M.M., Wilson, M.G., Emerson, K.G., and Glass, A.P. To be submitted to *Journal of Palliative Medicine.*

Abstract

Parkinson’s disease (PD) is the second most common age-related neurodegenerative disorder. Despite widespread recommendations for a palliative approach in the management of PD, little is known about what palliative needs are unmet by standard neurological care. This mixed methods study aims to 1) to determine the unmet palliative needs of PD patients as reported by patients and physicians, 2) to investigate the extent to which PD patients and neurologists agree on these unmet palliative needs, 3) to determine the relationship between patient-reported unmet palliative need and patients’ health-related quality of life (HRQoL), and 4) probe more in depth into factors hypothesized to affect PD patients’ HRQoL.

Forty-nine patients and 62 physicians were recruited for the quantitative survey, and 23 patients were qualitatively interviewed. While both patients and neurologists reported unmet palliative needs, significant differences between groups were found in all five palliative symptom groups: Physical $F(1)=48.91$, $p<0.0001$; Psychological $F(1) = 21.82$, $p<0.0001$; Social $F(1)=40.16$, $p<0.0001$; Financial $F(1)=52.01$, $p<0.0001$; and Spiritual $F(1) =44.06$, $p<0.0001$. Physical needs ($F=20.84$, $p<0.0001$) and Psychological needs ($F=9.02$, $p=0.005$) along with race ($F=3.42$, $p=0.03$) significantly predicted patient HRQoL. Two pervasive overarching themes across interviews included 1) lack of healthcare education and 2) need for more effective care coordination. Three prominent secondary themes identified included: 1) the importance of support groups; 2) the vital role of spirituality and religion; and 3) the narrow perceived role of the neurologist in PD care. These findings highlight the individuality of patient need as well as opportunities for palliative intervention.

Background

Parkinson's disease (PD) is an incurable neurodegenerative disease, requiring multiple clinicians for optimal long-term management (Langston, 2006; Lees et al., 2009; Tolosa et al., 2006). Numerous studies promote a palliative approach to the disease (Bunting-Perry, 2006; Hudson et al., 2006; Hughes et al., 1993) whereby the medical team focuses on improving quality of life through a holistic care approach, addressing the physical, psychological, social, financial, and spiritual aspects of disease (Meyers & Linder, 2003; Morrison & Meier, 2004; National Guideline Clearinghouse, 2013). This palliative care is most often provided, however, by neurologists employing basic palliative principles in practice (*Dying in America*, 2014), and most PD patients do not receive specialty palliative care from clinicians certified in palliative care until they are admitted to hospice at the end of life (Centers for Medicare & Medicaid Services, 2009).

Although palliative services can be accessed throughout the course of a serious illness, hospice is a type of palliative care provided to individuals with terminal conditions in the last six months of life (Giovanni, 2012; National Guideline Clearinghouse, 2013). The proportion of patients with neurodegenerative conditions (dementia and PD) on hospice has increased from 16% in 2004 to 19% in 2009, and the average length of stay for these patients is nearly double that of all other diagnoses (101 days vs. 56 days) (Centers for Medicare & Medicaid Services, 2009). The National Home and Hospice Care Survey has indicated that individuals with neurological diagnoses are more likely to be discharged live from hospice care than those with cancer-diagnoses (Kutner et al., 2002). These data indicate that a palliative approach is indeed beneficial to these patients, and PD patients may benefit from receiving these services earlier in the course of the disease. It is unknown, however, what palliative needs PD patients may have throughout the disease that are currently unmet by standard neurological care as well as how palliative symptoms and needs affect individual quality of life.

Objective

The first aim of the study is to determine the unmet palliative needs of PD patients as reported by patients and physicians, and to investigate the extent to which PD patients and neurologists agree on these unmet palliative needs. It is hypothesized that non-physical need categories, psychological and social needs in particular, will have more unmet need than the physical need category. It also is hypothesized that patients will report greater unmet need than physicians. A second aim of this study is to determine the relationship between patient-reported unmet palliative need and patients' health-related quality of life (HRQoL). Because palliative care focuses on improving quality of life (Meyers & Linder, 2003; Morrison & Meier, 2004; National Guideline Clearinghouse, 2013), it is hypothesized that patients with increased palliative need will report poorer HRQoL. The third aim of this study is to probe more in depth into factors hypothesized to affect PD patients' HRQoL with a focus on understanding patients' experiences, perceptions, expectations, and knowledge or awareness regarding their own palliative care needs.

Design

This is a mixed methods study, using an explanatory sequential design in which qualitative interviews with patients were used to inform and provide context for the quantitative survey findings. This mixed methods approach provides a more complete and comprehensive understanding regarding the complex nature of patient needs in PD than the use of one of these methods alone. Aims 1 and 2 were addressed through quantitative surveys, completed by PD patients and neurologists. Aim 3 was addressed through in-depth semistructured interviews with a subset of PD patients. Consistent with an explanatory sequential mixed method design, integration and interpretation of quantitative and qualitative data occurred at the end of the study, and meta-inferences drawn from the combined methods are presented in the Discussion and Conclusion sections of the paper. In line with this type of study design, meta-inferences relate to ways qualitative data inform and provide additional context and insight into understanding survey results (Creswell & Plano Clark, 2011).

Setting/Subjects

For the quantitative portion of the study, all surveys were available electronically, accessible through two URLs, depending on which version (patient or physician) the participant was accessing. Study information, including participant eligibility, was included in the email messages accompanying the survey information, and participants self-selected into the study. The study procedures and measures were approved by the University of Georgia Institutional Review Board prior to data collection.

G*Power 3.1 software was used to determine sample size for the quantitative portions of the study (Faul, Erdfelder, Buchner, & Lang, 2009; Faul, Erdfelder, Lang, & Buchner, 2007). It was determined a priori that, for a MANOVA analysis, 50 PD patients and 50 neurologists will be needed to detect a small effect size of 0.20 beween the five symptom groups with an alpha of 0.05 and a power of 0.80 (Faul et al., 2009; Faul et al., 2007; Peto et al., 2001). Enrollment continued until the target size for each sample was reached.

For the follow-up qualitative arm of the study, a purposive sample of between 20 and 30 individuals of ages, races, and durations of disease, representative of the general demographics of PD patients, were targeted for inclusion in the study to elicit a more comprehensive understanding of palliative symptoms and experiences than could be gained from a quantitative study alone (Creswell & Plano Clark, 2011). Sample size for the qualitative component was based on guidelines found in the literature and is in line with recent suggestions for sampling designs in mixed methods research and for qualitative studies that employ thematic analysis (Braun & Clarke, 2013; Onwuegbuzie & Collins, 2007).

Patient Participant Recruitment

Research indicates that those with PD constituted approximately 0.2% of the population in 2010 (Kowal et al., 2013; United States Census Bureau, 2010); therefore, a convenience sample of PD patients was used for the study (Onwuegbuzie & Collins, 2007). Individuals with PD were recruited through the American Parkinson Disease Association Georgia Chapter support group network as well as through neurology clinics and senior centers throughout the state. Eligibility criteria for PD patients included being at least 18 years old, having a self-reported diagnosis of PD, and being fluent in English. Support group leaders in the American Parkinson's Disease Association (APDA) network were asked to email the electronic survey link to their group members. Senior Centers were asked to post flyers with study information and the survey link.

For the qualitative portion of the study, the interview opportunity was presented to patient participants completing the survey in the final question of the measure. Participants had the opportunity to provide their contact information if they were interested in being contacted for an interview. From this pool of interested participants, a sample of 30 individuals, representative of the general demographics of PD patients were contacted to schedule a date in which consent was provided and the interview conducted. Capacity to consent was determined by the completion of a capacity to consent form following review of the general consent form; however no participants met criteria for this exclusion. Interviews were conducted in private locations convenient to each participant and according to availability in the participant's schedule. With the participant's permission, interviews were digitally recorded and transcribed verbatim.

Physician Participant Recruitment

Because of the specialization needed for neurologists and movement disorders specialists, recruitment of these clinicians targeted professional organizations with large proportions of these specialists. The National Parkinson Foundation is an organization comprised of a network of forty-one medical centers devoted to the care of individuals with Parkinson's disease. The Medical Association of Georgia is a statewide physician advocacy group with 7,800 members, including physicians specializing in neurology and movement disorders. Both of these organizations agreed to share survey information with their members electronically. Additional neurology clinics were identified through the American Academy of Neurology's database of Georgia neurologists. Eligibility for the physician survey included being over the age of 18 and being currently employed as a general neurologist or movement disorders specialist. Electronic surveys for clinicians were disseminated amongst centers in the National Parkinson Foundation network of professionals. The Medical Association of Georgia also shared the survey opportunity with the listserv of their members. Additional neurology clinics, identified through the American Academy of Neurology's database of Georgia neurologists, were called, and survey and study information was sent to physicians via email, fax, and in person.

Measurements

Patient Measures

Palliative need To measure palliative need, a 31-item survey was adapted from the 12-item Palliative Outcome Scale for Parkinson's, based on results from Hudson's study on the palliative needs of PD patients as well as Bunting-Perry's research on palliative care in PD

(Bunting-Perry, 2006; Hearn & Higginson, 1999; Hudson et al., 2006). In this measure, palliative needs were categorized into five domains (physical, psychological, social, financial, and spiritual) and were assessed through a 4-point Likert scale (with anchors Very Well to Poorly). Not Applicable was an option for those not experiencing a symptom. Content validity for the measure was assessed by a five-person panel of experts in palliative care and PD. Experts were asked to rate items as Essential, Useful but not essential, and Not essential. Items rated Useful but Not essential and Not Essential were researched in the literature regarding their importance in palliative need. After data collection, Cronbach's alpha was run for each group with and without each item. Alphas did not improve with the removal of any items, so all were retained. In the final measure, Cronbach's Alphas were calculated for all patient symptom categories with more than one item (Physical $\alpha = 0.88$, Psychological $\alpha = 0.93$, Social $\alpha = 0.94$, and Financial $\alpha = 0.88$), indicating good to excellent reliability of the items in the measure.

Health-related quality of life For the second aim of the study, individuals with PD also completed the PDQ-39, which is the most commonly used HRQoL measure for individuals with PD (Bushnell & Martin, 1999). Consistent with the Healthy People 2020 definition, HRQoL is defined in this study as the quality of the physical, mental, and social domains of life in the context of health and disease (*Health-Related Quality of Life and Well-Being*, 2010). Subscales were assessed via a 5-point Likert scale (with anchors of Never and Always) include mobility (10 items), activities of daily living (6 items), emotional well-being (6 items), stigma (4 items), social support (3 items), cognition (4 items), communication (3 items), bodily discomfort (3 items). To calculate the PDQ index score, for each of the eight dimensions, a dimensions score was calculated by summing the scores of each item in a given dimension and dividing that figure by the maximum possible score for that dimension, multiplied by 100. The Summary Index

Score was then calculated by summing the total scores for each dimension and dividing by eight. Lower scores reflected better HRQoL. Research examining the validity and reliability of the scale with 150 patients recruited from Seattle area neurology clinics have found acceptable internal consistency for most domains (Cronbach's α= 0.73 to 0.96), with the exception of the social support category, which had an internal consistency of 0.51. The PDQ-39 also had an acceptable test-retest reliability (from 0.86 to 0.96, $p<0.001$) (Bushnell & Martin, 1999). As an instrument used widely in palliative care practice and research, the PDQ-39 will complement the qualitative survey by providing a thorough quantitative assessment of palliative need and HRQoL.

Demographics Covariates included sex, age, race, income, duration of PD, and number of complementary therapies used. Age was typed into an open text box in the survey. Participants selected their race from a list of options, and income level was selected from a list of options used in the Behavior Change Consortium Demographics Questionnaire. Duration of PD was measured as a self-report of the number of years a patient had been diagnosed with PD. For complementary therapies, participants checked off any non-physician clinicians they had encountered in their PD care, and the sum of these clinicians was totaled to create the variable.

Qualitative The qualitative component of the project helped address Aim 2 and probed more in depth into factors hypothesized to affect PD patients' HRQoL with a focus on understanding patients' knowledge, awareness, and experiences of palliative need. Data collection involved in-depth face to-face interviews that were digitally-recorded and transcribed verbatim. The physical symptoms section of the semi-structured interview guide was developed based on domains included in the Needs at the End-of-Life Screening Tool (NEST) (Emanuel et al., 2001) and the PDQ-39 (Peto, Jenkinson, & Fitzpatrick, 1998). The NEST is a measure commonly used in palliative care to examine the subjective experiences of patients through multiple dimensions including physical, psychological, social, financial, and spiritual domains. The NEST questionnaire also inquires about communication and educational information provided by the physician (Emanuel et al., 2001). The semi-structured interview guide included the following four broad domains: 1) background information about the study participant, including length of time living in the current city and types of social support available; 2) access to formal care, including community health resources; 3); individual's diagnosis of PD, including events leading up to the diagnosis and the diagnosis itself; and 4) current PD stage and symptoms, including any perceived needs related to these symptoms. Broad, open-ended questions included follow-up probes to gather additional information as needed. Examples of an open-ended questions in the sample probe include:, "Can you discuss the appointment when your PD diagnosis was made?" and "What, if anything, could have improved that first appointment/experience?"

Physician Measures

Palliative need Physicians completed a survey to measure their perceived ability to address each symptom for a majority of their patients that was complementary to the one taken by patients. Cronbach's Alphas were calculated for all symptom categories with more than one item (Physical $\alpha = 0.89$, Psychological $\alpha = 0.84$, Social $\alpha = 0.85$, and Financial $\alpha = 0.67$). The alpha for the financial category items was slightly below the threshold for an acceptable value. However, since the consistency was good in the patient survey and removal of any items did not improve upon the reliability, all items in the category were retained for analysis.

Demographics Covariates included age, sex, physician specialty, years practicing as a physician, years working with PD patients, and number of complementary clinicians in practice.

Age was typed in to an open text box in the survey. Physician typed a number of years into a text box to record length of time practicing and length of time working with PD patients. For complementary therapies, participants checked off any non-physician clinician specialties that worked with them in practice, and the sum of these clinicians was totaled to create the variable.

Analysis Plan

Quantitative Analysis

SAS v. 9.3 (Cary, NC) was used for quantitative analyses. To retain as many participants as possible from the dataset, for each symptom category, if 25% or fewer items were missing for a participant, scores for those missing items were imputed from the average of remaining items in that category. The means and standard deviations for each category (e.g., physical, psychological, social, financial, spiritual) were calculated for each sample to determine the extent to which each category was reported as addressed or unaddressed by current care. Higher scores indicate greater unmet need for each symptom. Means and standard deviations were run for each symptom category by treating clinician type, duration of PD, number of complementary therapies used, and use of palliative services.

A MANOVA analysis was run to assess differences in reported palliative need between patients and physicians. A multiple regression analysis was run to determine the relationship between patient-reported unmet palliative need and patient HRQoL. In this regression, the PDQ index score served as the dependent variable, and the palliative symptom categories from the factor analysis served as the independent variables. Covariates selected for initial analysis included: sex, age, duration of PD, nurse treatment, social work treatment, physical therapist treatment, occupational therapist treatment, speech-language pathologist treatment, and chaplain treatment. Previous research has indicated that PD incidence and symptom intensity may vary based on these factors (De Lau et al., 2004; Lang & Lozano, 1998; Prizer & Browner, 2012). Covariates for a final reduced model were chosen through a backward selection process whereby variables with an $\alpha \geq 0.05$ were systematically removed from the model one by one until all remaining variables were significant. The sum of squares for the full model was 11,324.6 versus the reduced model of 11,138.8. The r^2 value indicated that the final model explained 0.78 of the variance in the dependent variable.

Qualitative Analysis

For the qualitative portion of the study, a codebook of pre-set "housekeeping" codes was developed prior to data collection, to assist with tagging, sorting, and organizing data for higher-level analysis. A priori codes were based on the study aims as well as domains found in the NEST (Emanuel et al., 2001). As analysis progressed, emergent codes were added to the codebook. All transcription and coding were performed by the primary researcher. Codes and emerging themes were discussed, refined, and verified through regular meetings with co-authors to enhance credibility of analysis. The NVIVO 10 software package was used for data management and to facilitate analysis.

Thematic analysis was used to identify patterns and recurrent themes in the data (Braun & Clarke, 2006; Fereday & Muir-Cochrane, 2006). It adopted an inductive and deductive approach (Fereday & Muir-Cochrane), where initial codes were developed based on previously established palliative care domains (e.g., Emanuel et al., 2001) and other literature used to inform the aims (Bunting-Perry, 2006; Hudson et al., 2006). Consistent with guidelines established by Braun & Clarke, 2006, analysis involved six recursive phases: 1) immersion in the data through repeated rereading of interview transcripts; 2) refinement of the initial codebook; 3) searching for themes among and across codes; 4) reviewing themes and linking these with relevant themes in the literature; 5) refining and naming the final overarching and secondary themes; and 6) writing the results. Analysis was considered complete when themes were refined and fully developed, and when no new themes or relevant data was identified in the interview transcripts.

Results

Quantitative Results

Seventy-five patients were recruited for the survey; however, only forty-nine datasets (65.3%) were complete and therefore retained for the study. As demographic data for both patients and physicians was collected at the end of the survey, there was not enough data on non-completers to determine whether any differences existed between them and completers. The average age was 66.4 (SD=10.4, range=45-83). The duration of PD since diagnosis ranged from 1 year to 25 years, with an average duration of 8.2 years (SD=5.1). Fifty-eight percent of the sample was male (n=28). Nearly ninety-four percent (93.8%) of the sample was white (n=45), 2.1% was African American (n=1), 2.1% was Asian (n=1), and 2.1% identified as Other (n=1) [Table 4.1].

Seventy-six physicians enrolled in the study; however, only sixty-two physicians (81.6%) had complete data and were included in the analysis. The mean age of the sample was 45.8 years (SD=10.4). Sixty percent of the sample was male (n=36), and nearly 92% specialized in Movement Disorders (n=55). The mean length of time practicing as a physician was 15.4 years (SD=10.3), and the mean length of time working with PD patients was 14.3 years (SD=9.3) [Table 4.2].

On the 100-point index scale for HRQoL (higher numbers indicate lower HRQoL), as measured by the PDQ-39, the mean index score for participants was 28.9 (SD=17.8). Participants reported seeing an average of 2.2 (SD=1.7) non-physician clinicians (e.g., nurse, social work, physical therapy, occupational therapy, speech therapy, and chaplain) in their Parkinson's care. Of the patients who responded to the item, only two (4.3%) stated that they had been treated by a non-terminal palliative care team before. Patients and physicians differed in how they ranked the level of need between groups. Patients reported the psychological need as being the greatest, followed by physical, social, spiritual, and financial need. Physicians ranked spiritual need as being most unmet, followed by physical, financial, psychological and social [Table 4.3].

In order to assess the differences between patient and physician reported need, a MANOVA analysis was run for the symptom domains. Significant differences were found in all five palliative symptom groups: Physical $F(1)=48.91$, $p<0.0001$; Psychological $F(1) = 21.82$, $p<0.0001$; Social $F(1)=40.16$, $p<0.0001$; Financial $F(1)=52.01$, $p<0.0001$; and Spiritual $F(1) =44.06$, $p<0.0001$. In all need domains, physicians reported their patients having greater unmet palliative need than patients reported experiencing [Tables 4.3 & 4.4].

Palliative need and health-related quality of life A multiple linear regression was calculated to predict HRQoL from the Physical, Psychological, Social, Financial, and Spiritual symptom categories. Of the five groups, Physical ($F = 85.21$, $p<0.0001$) and Psychological ($F=17.9$, $p=0.0001$) symptom categories were found to significantly predict HRQoL. The full model was then run, including age, sex, race, years since diagnosis, income, and number of non-physician clinicians seen.

After the backward selection process, only race remained in the final model. The order of covariate removal was years since diagnosis, number of complementary clinicians, and age. In the final model, Physical needs ($F=20.84$, $p<0.0001$) and Psychological needs ($F=9.02$, $p=0.005$) along with race ($F=3.42$, $p=0.03$) significantly predicted patient HRQoL [Table 4.5].

Qualitative Results

Thirty-eight of the targeted survey respondents provided their contact information and gave their consent to be contacted for a potential follow-up qualitative interview. Thirteen participants could not be reached; one was unavailable for an interview; and one participant had such severe speech and communication difficulties that he could not participate. This resulted in a total of 23 interview participants for the qualitative arm of the study. The average length of interview was 54:58, and interview length ranged from 28:56 to 83:21. Thematic analysis identified two major gaps in patients' care not captured by the survey. Two pervasive overarching themes found across all interviews included: 1) lack of healthcare education and 2) need for more effective care coordination. Three prominent secondary themes also were identified that have important implications for patients' HRQoL and ability to successfully manage and cope with their illness. These themes included: 1) the importance of support groups; 2) the vital role of spirituality and religion; and 3) the narrow perceived role of the neurologist in PD care. These findings are outlined below.

Lack of healthcare education Qualitative analysis showed that patients' received minimal instruction or educational materials or resources from their neurologists to assist them manage their care. In many cases, patients reported that they did not remember receiving the information and concluded that the information either was not provided or was not memorable or useful enough to make an imprint. The following statements were in response to a question regarding whether or not patients' neurologists provided information and resources on PD at diagnosis.

> I don't remember that neurologist doing it.
>
> I don't remember. So that means there wasn't much.

> I really don't remember what all the first person [neurologist] might have given me. I know the second one didn't give me anything.

Several patients indicated that information they learned on their own was more useful than that provided by their neurologist.

> I found it on my own.
>
> It's been more on my own picking things up.
>
> He told me to rotate my arm once a day. . . I've since learned more on my own that I believe to be better information than I was getting from him.

Some patients reported that neurologists placed too much emphasis with regard to education on medications and neglected other important aspects of care. One patient stated, "I think they [neurologists] need to take a bigger role in making people aware of things that can help them besides medications." Another who indicated only receiving educational information related to medications said, "She (the neurologist) gave me a list of medications that I can't take, but I have a file folder full of information that I've gotten from the Parkinson's Foundation and various other organizations." A third patient expressed a common sentiment: "I think they [physicians] are terrible about making you aware of support groups, the value of physical therapy, exercise, [etc.]."

Need for more effective care coordination Another pervasive theme related to a perceived lack of healthcare education was the need for more effective care coordination. This theme includes two subthemes: 1) limited communication among providers and 2) challenges managing and integrating care (i.e., coordinating multiple treatments, resources, and specialists).

Limited communication among providers Several participants did not believe that their physicians ever communicated with one another:

> I don't think there's any [communication]; I don't think they've ever communicated.
>
> I don't think they communicate much at all.
>
> It'd be nice if they had a conference call once in a while.

One patient accepted the lack of communication among her providers based on her perception that her physicians were too busy to communicate with one another: "I wish that would happen, but I think they're both so busy that I understand that they don't." Others indicated that they felt responsible for communicating healthcare information among their providers.

> I don't really know that there's a procedure that my notes from one place to go another unless I get them there.
>
> I have to do it . . . by pushing each one to send the information to the other.
>
> I do a lot more work with trying to pull everybody together. . . I doubt that they ever communicate [unless I convey the information].
>
> I know that when I see the neurologist and I see the internist, I tell the internist what the neurologist is doing and vice versa. So I try to keep them up to date.

Some patients assumed that their providers communicated but had no evidence:

> I don't know if they speak, but their offices probably fax things back and forth in this day and age.
>
> I'm almost certain they document everything in the system.

Challenges managing and integrating care Related to a lack of communication among providers was a common perception among patients that care is not well integrated across the healthcare system. Many indicated that coordinating care was a burden that primarily fell on them or a family member and was not a role that they were well equipped to manage. One patient expressed a common frustration:

> My main complaint about the current medical system is that we've really taken away the medical manager, the HMO, and I have to be my own HMO. I have to go find the physician, interview the physician, and sit down with them. Make sure that they're giving us the right care. Ask if there's somewhere else we should go. And all of that falls on my shoulders now.

Similarly, another stated:

> In today's medical system . . . the biggest challenge is to know who's in charge. And there's really no one in charge of it but me, and I gotta get all these people that don't speak each other's language or talk to each other to coordinate and make sure they're all thinking holistically. It is hard.

One patient noted that this problem is exacerbated for people with PD and those with other complicated chronic conditions that require coordination among multiple treatments, providers, and resources:

> My endocrinologist. . . can't tell me anything about my foot. I have to go to a podiatrist or the podiatrist has to send me to the ear nose and throat guy. The ear nose and throat guy sends me to the general surgeon. The general surgeon sends me back to my primary care physician. And I have to coordinate all of that.

Secondary Themes

Importance of support groups The importance of support groups was one of three secondary themes identified in this study which overlap with the overarching themes described above and also have important implications for PD patients' HRQoL and ability to successfully manage and cope with their illness. Given that patient participants were recruited from support groups, it is not surprising that support groups were identified as an important resource in this study. Key insights from the current analysis include the importance of support groups in providing needed education and referrals not typically offered by patients' providers, especially in the area of psychosocial support, and evidence of the critical role that these groups play in helping patients cope with their illness. One patient stated, "There's a sense of sharing and you're not in it alone." Another spoke of the "healing power" of attending the group. Unfortunately, data from this study showed that few patients were connected to this important resource through their physicians.

Vital role of religion and spirituality Another key finding from qualitative analysis was the vital role of religion and spirituality in helping patients manage and cope with their illness. Although patients indicated relatively low levels of unmet spiritual need the survey as well as in the qualitative interview, many discussed at length the importance of spirituality and religion in their health management. The following statements are reflective of many:

> I think faith gets us through whatever it is we have to do. God's given me this challenge for a reason.
>
> I pray for [God] to give me emotional, mental, and physical strength to get through things.

Although the level of importance of spirituality and religiosity varied among participants, most said that they would appreciate having their providers ask about their spiritual needs. However, as one participant noted, "Everybody is afraid to talk about it."

The limited perceived role of the neurologist in PD care A final theme related to patients' perceptions regarding the role of their neurologist. Although all participants recognized the importance of having their psychosocial as well as their physical and medical needs met, most did not view their neurologist as a resource for addressing these needs. When asked what role they expected their neurologist to play in their PD care, one patient said, “I expect them to put their primary interest in… what I’m medically and what they might do with pills or surgery.” Similarly another stated, “I guess just keep prescribing my medications.” As indicated in data presented above, some patients believed that neurologists should adopt a more holistic approach to care and address needs other than just medications. However, the majority had a more narrow view of the neurologist as a medications specialist--someone who “really specializes [in] their knowledge of the medications.” This finding may provide some insight into the relatively low reports of palliative need in the quantitative surveys, as most patients may not see their neurologist as a resource to address issues outside of strictly physical needs. These results are discussed more in depth below.

Discussion

While previous research has examined potential palliative needs of PD patients, no study yet has focused on measuring the level of palliative need of PD patients as reported by both patients and neurologists. The results of this study suggest that PD patients experience palliative need throughout the course of the disease, and numerous symptoms, particularly non-physical needs, may be more difficult for neurologists to address. Interestingly, neurologists reported that their patients had greater palliative need than the PD patient respondents; however, this may be due to patients being recruited from support groups, possibly giving them access to more comprehensive care, services, and education than the full population of patients neurologists treat.

In the survey, patients and physicians also differed in how they ranked the level of need between groups. Patients reported the greatest amount of unmet need psychologically, followed by physical, social, spiritual, and financial need. This finding supports previous research indicating that emotional support related to ongoing coping with the illness as well as psychological needs, such as depression, are common unmet need in PD care which strongly related to HRQoL (Cubo et al., 2002; van der Eijk, Faber, Shamma, Munneke, & Bloem, 2011a). Physicians, however, reported spiritual need as being most unmet, followed by physical, financial, psychological and social. Significant differences between these symptom categories also varied by participant group. These results may highlight the individuality of patient symptoms and needs in PD, as the clinical presentation of symptoms can vary greatly between patients (Prizer & Browner, 2012). A previous study, focusing on end-of-life palliative care only, found disagreement as well between patients and physicians regarding needs and preferences at the end-of-life (Steinhauser et al., 2000). These findings highlight the challenges of providing comprehensive, and coordinated care to PD patients, and they stress the importance of communication between physicians and their patients to assess patient-identified needs and clinical priorities in care.

Only Physical and Psychological symptom categories were significant predictors of HRQoL in the multiple regression. These findings may be due to numerous factors. Physical and psychological symptoms may be the most difficult for patients to control as the disease progresses or they may be the most distressing symptoms. Also, the PDQ-39 focuses primarily on physical, psychological, and cognitive symptoms and does not include comparable quality of life measures for social, financial, and spiritual aspects of health (Jenkinson, Fitzpatrick, Peto, Greenhall, & Hyman, 1997). The social section of the PDQ-39 pertains specifically to stigma and support from friends and family, and it does not consider factors such as locating community and financial resources, assistive technology needs, and care coordination needs. As patients in the qualitative branch of the study did note numerous symptoms in these other domains that affected their HRQoL and coping with the illness, this finding may indicate a need for additional studies that better understand the impact these domains can have on patient HRQoL.

Despite the relatively low level of need reported by patients in the survey, analysis of qualitative interviews indicated that there may have been greater levels of need than quantitatively reported. Numerous patients who quantitatively reported low levels of need in symptom categories discussed previously unreported areas of palliative need in qualitative interviews, particularly in the social domain of need. This may be due in part to a limited personal assessment of the presence of some needs or a lack of knowledge of how they might be improved. This finding highlights the need for interdisciplinary clinical assessment of need, as patients may not be aware of all areas in which treatments may be available and symptoms and needs can be improved. Interviews also indicated that the patient survey estimates of non-physical need may be conservative as many patients do not expect their physicians to address needs beyond their physical symptoms.

Both patients and physicians reported low levels of social need quantitatively; however, two of the primary themes that emerged in qualitative interviews included the need for educational information about the disease and resources and care coordination gaps, both of which fell into the Social domain. Numerous participants noted that they received very little educational information directly from neurologists. Most patients located information on the disease, treatments, programs, and resources from the internet or from support groups. This finding mirrors another study on themes related to a patient-centered approach in PD, where patients expressed the need for tailored information from their physicians regarding education, treatment options, and programs and therapies to manage symptoms (van der Eijk et al., 2011a).

Despite low reports of need in care coordination quantitatively, interviews revealed significant gaps in coordinating care between practitioners. A majority of interviewed patients noted that they had several conditions for which they were receiving treatment, but very few of them knew or believed that their clinicians communicated among one another. For some patients, this resulted in frequent changes in medications between neurology visits with different practitioners, and one patient noted that she received contradictory diets from two of her physicians who were not communicating about their treatment recommendations. The importance of care coordination in PD treatment has been emphasized in previous research as one of the highest ranked indicators of the quality of care (Cheng et al., 2004). Because neurology clinics vary in size and clinical resources, this may be an opportunity for palliative care intervention in PD treatment.

The role of spirituality and religion in healthcare is a growing field in research and in clinical care. A majority of patients in interviews noted that spirituality plays a very important role in how they manage and cope with health challenges; however, no participant reported being asked about spiritual needs at appointments, with the exception of one patient who thought he may have been asked if he had any religious beliefs that might limit possible treatments. A study on family physicians' views of spirituality in clinical practice noted that doctors differ in their views on and comfort in discussing these matters with patients; however, they do understand the integral role that spirituality plays for many patients (Ellis, Campbell, Detwiler-Breidenbach, & Hubbard, 2002). A separate study using patient focus groups found that, although patients do not necessarily expect physicians to discuss spirituality, they want to be asked about coping and support strategies, including those related to spiritual health (Hebert, Jenckes, Ford, O'Connor, & Cooper, 2001). This research, as well as the results of the present study, highlight the need for chaplaincy in clinical practice, and palliative care teams may be promising options to address this need.

One possible explanation for the discordance between the survey results and these qualitative themes is that patients do not seem to view their neurologists as being responsible for addressing non-physical care needs. When asked in interviews about the role of their neurologist, most patients responded that they were for medication management alone. As a result, many patients indicated that they seek information, resources, and treatments independently of their medical appointments. While patients are encouraged to advocate for themselves in their care, the ideal model is more likely a compromise of these extremes, where patients can work with their physicians to receive tailored information and recommendations for resources. Recent literature in PD management advocates a participatory approach, where physicians and patients work collaboratively in the long term management of the disease (van der Eijk, Nijhuis, Faber, & Bloem, 2013). This collaborative approach is patient-centered, focusing on the symptoms and needs affecting individual HRQoL and providing treatment based on patient preferences. Palliative care teams currently use this participatory model in practice to work with patients in coordinating their care throughout chronic disease, and these palliative programs may be well-suited to assist in the ongoing needs of PD patients.

There are several limitations to the present study. Because patients were recruited from support groups and neurologists were recruited primarily from specialist organizations, sampling bias may be an issue. Specifically, these patients are likely better informed of resources than the general PD population. The physician participants come primarily from NPF Centers of

Excellence which, because of the clinical focus and expertise of the NPF, may provide participating neurologists with enhanced access to interdisciplinary team care than most neurologists. This potential sampling bias may have resulted in more conservative estimates of palliative needs than would be found in PD patients outside of support groups and without access to neurologist specialist care. Despite the potential for bias, participants still noted numerous palliative needs. This may indicate that patients in areas with more limited access to support groups, specialists, classes and therapies, may have greater levels of unmet palliative need. The self-report nature of the survey may lead to inaccuracies due to recall bias; however, similar surveys exist and have been used in research to assess patient symptoms and physician referrals to palliative care (Ahluwalia & Fried, 2009; Jenkinson et al., 1997). No standardized measures were available to measure the longitudinal palliative need of PD patients in the five primary domains of palliative care; therefore, one was developed for the study. Additional adjustments to the measure as well as validity and reliability testing are needed, however, to develop a standardized scale to better measure this need in this population. Because of the limited prior research on this subject, this study focused on a cross-sectional assessment of palliative need, and as a result, was exploratory in design.

In future studies, more representative samples should be used to examine the palliative need of this population. Additionally, although this study indicates that PD patients do have some palliative need, additional research is needed to examine whether a palliative model of treatment, specifically, would be beneficial in this population. Future studies should also examine the most effective implementation of palliative care consultations in the long-term treatment of PD.

Conclusions

Overall, this study found that patient palliative needs and preferences for care vary significantly among individuals. While all interview patients sought educational information, few were provided the information directly from their physicians. Although patient self-advocacy is encouraged in health-maintenance, practitioners may want to consider working to guide patients collaboratively in locating information and developing a plan of care tailored to their needs. These results corroborate the findings of van der Eijk, M. et al, who noted the need for a collaborative patient-centered model of care for individuals with PD (van der Eijk et al., 2011a).

Despite the ranging needs of PD patients, not all neurologists have access to interdisciplinary teams or feel comfortable managing issues in psychological, social, financial, or spiritual care domains. The reported levels of need in these non-physical symptom categories highlight the importance of palliative care involvement throughout the course of the illness. The interdisciplinary team involvement of palliative care may be best equipped to supplement standard neurology care in PD, specifically targeting the potential educational, care coordination, and spiritual needs of this complex group of patients.

Tables

Table 4.1 Demographic Characteristics of Patient Survey Participants (N=49)

	Survey Participants		Interview Participants	
Characteristic	**M**	**SD**	**M**	**SD**
Age (years)	66.4	10.4	66.2	10.1
Duration of PD (years)	8.2	5.1	8.1	3.9
Quality of Life Index Score	28.9	17.8	21.7	13.1
Allied Health Clinician Referrals	2.2	1.7	2.23	1.52
	N	**%**	**N**	**%**
Sex*				
Male	28	58%	13	57%
Female	19	40%	10	43%
Annual Household Income**				
$0 – 19,999	1	2.1%	1	4%
$20,000-29,999	4	8.5%	1	4%
$30,000-39,999	6	12.8%	2	11%
$40,000-49,999	4	8.5%	2	11%
$50,000-59,999	3	6.4%	2	11%
$60,000-69,999	0	0%	0	0%
$70,000-79,999	2	4.4%	1	4%
$80,000+	19	40.4%	10	53%
Race				
Black or African American	1	2.1%	1	4%
White or European American	45	93.8%	22	96%
Asian or Asian American	1	2.1%	0	0%
American Indian	0	0%	0	0%
Mixed or Multiple Races	0	0%	0	0%
Other	1	2.1%	0	0%
Referrals to Non-terminal Palliative Care*	2	4.26%	1	4%

*2 missing values

**10 missing values

Table 4.2 Demographic Characteristics of Physician Survey Participants (N=62)

Characteristic	**M**	**SD**
Age (years)	45.8	10.4
Length of time as physician (years)	15.4	10.3
Length of time working with PD patients	14.3	9.3
Complementary clinicians in practice	2.2	1.7
	N	**%**
Sex		
Male	36	60%
Female	24	40%
Movement Disorders Specialist		
Yes	55	91.7%
No	5	8.3%
Refer to Non-terminal Palliative Care		
Yes	32	54.2%
No	27	45.8%

Table 4.3 PD Patient and Physician Mean Scores and Standard Deviations on Palliative Need by Category

	Patient			Physician		
Need Category	M	SD	Rank	M	SD	Rank
Physical	1.38	0.76	2	2.25	0.54	2
Psychological	1.48	0.99	1	1.88	0.43	4
Social	1.19	1.03	3	2.11	0.43	5
Financial	0.98	1.19	5	2.31	0.35	3
Spiritual	1.06	1.39	4	2.73	0.98	1

Table 4.4 Multivariate Analysis of Variance of Palliative Need as Indicated by PD Patients and Physicians

Source	*df*	*SS*	*MS*	*F*	*p*	r^2
Physical	1	20.65	20.65	48.91	<0.0001	0.31
Psychological	1	12.55	12.55	21.82	<0.0001	0.16
Social	1	23.67	23.67	40.16	<0.0001	0.26
Financial	1	41.79	41.79	52.01	<0.0001	0.32
Spiritual	1	60.97	60.97	44.06	<0.0001	0.28

Table 4.5 Summary of Multiple Regression Analysis to Predict Quality of Life

	Full Model				Reduced Model			
Variable	*B*	*SE B*	*F*	*p*	*B*	*SE B*	*F*	*p*
Physical	12.38	2.76	20.09	<0.0001	12.02	2.63	20.84	<0.0001
Psychological	7.90	2.80	7.97	0.008	8.06	2.68	9.02	0.005
Social	-0.89	2.51	0.13	0.72	-0.20	2.44	0.01	0.94
Financial	-2.21	2.19	1.02	0.32	-2.22	1.82	1.49	0.23
Spiritual	0.82	1.31	0.39	0.54	1.15	1.21	0.89	0.35
Race			3.15	0.04			3.42	0.03
White or European American	0	0			0	0		
Black or African American	-9.94	9.41			-9.68	9.38		
Asian or Asian American	13.39	12.60			8.70	11.09		
Other	33.40	11.57			29.82	9.87		
Age	-0.20	0.17	1.32	0.26				
Complementary Clinicians	0.66	1.02	0.42	0.52				
Years Since Diagnosis	0.16	0.30	0.29	0.59				
R^2		0.80				0.78		

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CHAPTER 5

USING SOCIAL EXCHANGE THEORY TO UNDERSTAND BARRIERS AND FACILITATORS TO NON-TERMINAL PALLIATIVE CARE REFERRAL[2]

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[2] Prizer, L.P., Gay, J.L., Perkins, M.M., Wilson, M.G., Emerson, K.G., and Glass, A.P. To be submitted to *Palliative Medicine.*

Abstract

Background

A palliative approach is recommended in the care of PD patients; however, many patients do not receive this care unless they are referred to hospice near the end of life. Physician knowledge and attitudes about palliative care have been shown to influence referrals for patients with chronic disease, and as palliative care is commonly equated with hospice, negative physician perceptions may affect early referrals for PD patients to non-terminal palliative care.

Aim

The objective of this study is to use Social Exchange Theory to examine the association between neurologist-perceived costs and benefits of palliative care referral for PD patients and their actual palliative referral practices.

Design

A cross-sectional survey study of neurologist perceptions of the costs and rewards to palliative care referral.

Setting/Participants

Sixty-two neurologists recruited from the National Parkinson Foundation, the Medical Association of Georgia, and the American Academy of Neurology's clinician database.

Results

There was a significant difference between the mean scores, with participants reporting stronger endorsement of the rewards (M=3.34, SD=0.37) of palliative care referrals than the costs (M=2.13, SD=0.30) (t(61)= -16.10, p=<0.0001). A Poisson regression found that perceived costs, perceived rewards, physician type, and the number of complementary clinicians in practice were significant predictors of palliative care referral.

Conclusions

Physicians may be more likely to refer patients to non-terminal palliative care if they believe the rewards from the referral will outweigh any costs. Initiatives to educate neurologists on the benefits and availability of non-terminal specialist palliative services could potentially improve patient access to this care.

Background

Parkinson's disease (PD) is a chronic, neurodegenerative illness, which can slowly develop over the course of several decades (Langston, 2006; Lees et al., 2009; Tolosa et al., 2006). Because there currently is no cure for PD, treatments are palliative in nature, focusing on symptom management and improving quality of life (Bunting-Perry, 2006; Hudson et al., 2006). Palliative care is a medical specialty focusing on addressing symptoms in a holistic manner by an interdisciplinary team, considering the physical, social, emotional, and spiritual well-being of the patient (National Guideline Clearinghouse, 2013). It has been shown to reduce health care costs and improve clinical outcomes for patients with chronic and terminal illnesses, and it is recommended throughout the duration of serious illness (*Dying in America*, 2014; Morrison et al., 2008; Temel et al., 2010). This palliative approach from an interdisciplinary team is recommended in the care of PD patients, and most neurologists employ basic palliative skills in practice (*Dying in America*, 2014). Although a recent Institute of Medicine report recommends that any patients with a serious or terminal illness have access to palliative care throughout the full course of their disease, many PD patients do not receive palliative care from an interdisciplinary team of specialists unless they are referred to hospice near the end of life *(Dying in America, 2014)*.

Physician knowledge and attitudes about palliative care have been shown to influence referral patterns for patients with chronic disease in general (Bestall et al., 2004). However, several studies have found that physicians commonly associate palliative care strictly with end of life care, limiting the number of referrals to the service (Cherny, 2009; Fadul et al., 2009; Rodriguez et al., 2007). In one qualitative study, physician respondents noted that palliative care was often perceived as "pulling the plug," and very few thought palliative care had a role outside of terminal care (Rodriguez et al., 2007). A separate study on referral patterns indicated that physicians frequently underestimate the proportion of their patients who are eligible for non-terminal palliative care (Ahluwalia & Fried, 2009). No study yet has examined the perceptions of neurologists regarding palliative care for PD patients.

As physicians generally serve as the gatekeepers to these services, limitations in their understanding will subsequently impact their patients' knowledge, access, and utilization of the services. Because of the chronic nature of PD and the potential benefit of palliative care, it is important to understand the knowledge and attitudes of neurologists towards non-terminal palliative care.

Aim

Social Exchange Theory (SET) is a value expectancy theory, involving a balance between individual expectations regarding the outcomes of performing an action as well as their subjective values or rewards about those outcomes (Sutton, 1987). SET proposes that individuals are motivated to interact with another person in a specific activity if they expect a positive outcome from the interchange. If the benefits of the outcome are more rewarding than the cost of the activity, the relationship will be valued and the individual will be more likely to engage in the collaborative behavior again in the future (Shortell, 1974). With regard to the current project, physicians may be expected to refer patients to palliative care if they believe the specific rewards from the referral will outweigh any costs. The objective of this study is to use SET to examine the association between neurologist-perceived costs and benefits of palliative care referral for PD patients and their actual palliative referral practices.

Design

Measurements

Perceived costs and rewards An online quantitative survey was used to measure physician perceptions regarding the costs and rewards to palliative referral via short-answer statements using a four-point Likert scale (with anchors 1-*strongly disagree* to 4-*strongly agree)*. Statements of potential costs and benefits were drawn from previous SET literature on physician referral patterns, from research on palliative care and PD, and from studies on palliative care referral in general (Ahluwalia & Fried, 2009; Bestall et al., 2004; Broom, Kirby, Good, Wootton, & Adams, 2012; Forrest et al., 2000; Kinchen, Cooper, Levine, Wang, & Powe, 2004; Shaw, 2010; Shortell, 1974; Shortell & Anderson, 1971; Walshe et al., 2008). The Cronbach's alpha for the rewards category was good at 0.84; however, the alpha for the costs group of items was 0.37 (Gliem & Gliem, 2003). Removal of any cost items did not improve reliability. Pearson correlation coefficients and separate Kruskall-Wallis tests were run between each individual SET item and the independent variables and covariates to determine which, if any, cost items did impact palliative referrals. Individually, many of the cost items were endorsed by physicians and were also associated with referral practices, so a decision was made to retain all items in the cost group. The clinician survey was delivered via emailed web link and was completed online anonymously. Examples of some of the cost and reward statements are as follows: "A palliative referral could lead to a loss of my autonomy in patient care," "The service may improve patient/family satisfaction," "Palliative care may be able to meet patient needs that I cannot address," "PD patients would not be interested in palliative care."

Palliative care referrals Physicians self-reported the estimated number of PD patients they referred to non-terminal palliative care on an annual basis.

Demographics Demographic variables included age, sex, physician type, years in practice, years working with PD patients, and the number of complementary clinicians in practice. For type, each neurologist indicated whether or not he or she was a Movement Disorders Specialist. Physicians reported the number of years in practice and years working with PD patients. For complementary therapies, physicians indicated any non-physician clinicians that worked directly in their practice for a list of different specialties, and the sum of these was totaled to create the variable. Previous research on physician factors that influence care has indicated that physician type, sex, and years in practice may impact palliative and end-of-life care referrals (Ahluwalia & Fried, 2009; Carver et al., 1999; Dalal et al., 2011). As the clinical influence of complementary clinicians addresses additional PD symptoms, access to these clinicians reduce the need for a palliative interdisciplinary team and subsequently affect referrals (Prizer & Browner, 2012).

Analyses

SAS v. 9.3 (Cary, NC) was used for analysis. Means and standard deviations for the pro statement group and for the con statement group were run, and Cronbach's alphas were calculated for pro and con item groups. A paired t-test was run to determine whether the mean pro and con scores for physicians were significantly different.

To determine whether these perceived barriers and facilitators potentially limit palliative care referrals, a Poisson regression was run with the number of non-terminal palliative care referrals as the dependent variable and means of the pro and con statement groups as the independent variables. A Poisson regression was used because the palliative referral variable included count data. Covariates included in the initial model included: physician type, sex, years in practice, years working with PD patients, and the number of complementary clinicians in practice. Covariates for a final model were chosen through a backward selection process whereby variables with an $\alpha \geq 0.05$ were systematically removed based on highest p-value using the Type III table from the model one by one until all remaining variables were significant.

Setting/Participants

G*Power 3.1 software was used to calculate sample size (Faul, Erdfelder, Buchner, & Lang, 2009; Faul, Erdfelder, Lang, & Buchner, 2007), determining that for a Poisson regression, 60 neurologists were needed to detect a small effect size of 0.20 with an alpha of 0.05 and a power of 0.80 (Faul et al., 2009; Faul et al., 2007; Peto et al., 2001). To compensate for expected loss and missing data, the recruitment goal was set at 65 neurologists.

To recruit neurologists, electronic surveys were disseminated amongst centers in the National Parkinson Foundation network of professionals. The Medical Association of Georgia also shared the survey opportunity with the listserv of their members. Additional neurology clinics were identified through the American Academy of Neurology's database of Georgia neurologists. These clinics were called and survey and study information was sent to physicians via email, fax, and in person. Eligibility for the physician survey included: being over the age of 18 and being currently employed as a general neurologist or movement disorders specialist. Participants self-screened for eligibility.

Results

Seventy-six physicians enrolled in the study; however, only sixty-two physicians (81.6%) had complete data and were included in the analysis. As demographic data for physicians was collected at the end of the survey, there was not enough data on non-completers to determine whether any differences existed between them and completers. The mean age of the sample was 45.8 years (SD=10.4). Sixty percent of the sample was male (n=36), and nearly 92% specialized in Movement Disorders (n=55). The mean length of time practicing as a physician was 15.4 years (SD=10.3), and the mean length of time working with PD patients was 14.3 years (SD=9.3). Just over half of the sample indicated that they did refer PD patients to non-terminal palliative care (n=32, 54.2%). Of those referring physicians, the average number of PD patients referred annually to non-terminal palliative care was 4.34. The average number of complementary clinicians in practice was 3.8 (SD=1.88) [Table 4.6].

A paired samples t-test was conducted to compare the cost and reward means. There was a significant difference between the mean scores, with participants reporting stronger endorsement of the rewards (M=3.34, SD=0.37) of palliative care referrals than the costs (M=2.13, SD=0.30) (t(61)= -16.10, p=<0.0001). Bivariate analyses were run to determine whether mean number of palliative referrals differed by level of agreement with individual cost and reward statements. Ten items yielded significant results, six of nine cost statements and four of nine rewards [Table 4.7].

A Poisson regression was run to determine whether endorsement of cost and reward statements was predictive of the number of palliative care referrals. Covariates in the full model included age, sex, physician specialty, years practicing as a physician, years working with PD patients, and the number of complementary clinicians in practice. Backwards selection of covariates was then used to remove non-significant covariates one by one. Covariates were removed by highest p-value in the following order: years practicing as a physician, sex, years working with PD patients, and age. The final reduced model included perceived costs, perceived rewards, physician type, and the number of complementary clinicians in practice. In this model, both perceived costs ($p<0.0001$) and rewards ($p<0.0001$) remained significant predictors of palliative care referral [Table 4.8].

Discussion

This is the first study of the perceptions of palliative referral of neurologists caring for individuals with PD. The significantly positive perceptions of the rewards of specialist palliative care are consistent with a growing emphasis on the palliative needs of PD patients (P. Bede, D.Ó. Brannagáin, S. Lorenzl, D.J. Oliver, & O. Hardiman, 2011; Hudson et al., 2006; Miyasaki, 2013; Wilcox, 2010). Although neurologists endorsed more rewards than costs to referral, only a slight majority reporting actually referring patients to non-terminal palliative care, and those who did referred an average of only 4.34 patients over the last year. This may be indicative of differing opinions on most appropriate referrals for PD patients as well as of varying geographic availability of specialist non-terminal palliative care services (Glass & Burgess, 2011; Meier & Beresford, 2008; Morrison et al., 2005).

As anticipated from a social exchange theory framework, greater perceived rewards of palliative referrals were predictive of increased numbers of palliative referrals, and perceived costs were associated with fewer referrals (Shortell, 1974). Physicians may be more likely to refer patients to non-terminal palliative care if they believe the rewards from the referral will outweigh any costs. The number of complementary clinicians working with the neurologist was also found to be significantly positively associated with palliative care referrals. This may suggest that neurologists who currently collaborate with other disciplines in patient care may be more likely to refer patients to additional complementary specialties, such as palliative care. Positive experiences with an interdisciplinary team may lead to reduced concerns over losing autonomy in patient care and over issues in communication between clinicians. Future research may want to examine whether the inclusion of palliative care professionals in the interdisciplinary care of PD patients may improve the use of these services in standard PD management.

This study also examined how individual perceived costs and barriers of referral may affect subsequent referrals, identifying significant factors involved in the referral process. This information may be used to aid palliative care programs in better working with neurologists to address patient needs. Significant cost items related to three primary themes: concerns about increased complications in managing PD patients alongside a palliative team, lack of knowledge about or availability of programs, and the perception that palliative needs were already well-addressed by the neurologist. Significant perceived rewards related to positive previous professional and patient related experiences with palliative care as well as perception of improved coordination of patient care.

All three themes noted as costs of referral mirror the results of a similar survey conducted in Australia on oncologist referral practices to palliative care (C. Johnson, Girgis, & Currow, 2008). In that study, primary reasons for non-referral included the perceptions that the oncologist could treat all symptoms and provide the same level of care as specialist palliative services; the physician did not have a good relationship with services or they were of poor quality; and there were limited or no specialist palliative services available to patients. Factors associated with increased likelihood of palliative referral, in that study, included female sex of the physician, over ten years of practicing in the specialty, referral for the purpose of interdisciplinary management of symptoms, and the availability of specialist palliative services (C. Johnson et al., 2008). The present study is innovative in that it is the first to examine neurologist-associated costs and rewards of specialist palliative referral. This information also provides insight into opportunities for enhanced education for neurologists regarding the potential benefits of palliative care for PD patients.

Limitations of the study include a sampling bias of recruiting neurologists primarily from the National Parkinson Foundation (NPF). Because of the NPF's focus on interdisciplinary treatment of PD, these specialists may have increased access to interdisciplinary team care and may report more positive perspectives of palliative care than neurologists who are not associated with the NPF. The sample also consisted primarily of specialists in Movement Disorders, and may thusly not be representative of the perspectives of general neurologists. Future studies should consider the examination of perceptions and attitudes of general neurologists regarding referral of PD patients to non-terminal palliative care. The self-report nature of the survey may also bias the results; however, similar surveys have been used to examine perceptions and referral practices of physicians previously (Brickner, 2004; C. Johnson et al., 2008). Further research on this subject should include the systematic chart review of PD patients for more objective estimates of actual palliative care referral practices.

Conclusion

Although a palliative approach is largely recommended for the ongoing care of PD patients, neurologist-based referrals to non-terminal specialist palliative care are still limited. As gatekeepers to palliative services, physicians play an integral role in providing patient access to non-terminal palliative care. Perceived costs and rewards to palliative referral are significantly associated with the numbers of PD patients referred to specialist care and may offer insight into opportunities for physician education that would enhance appropriate referrals for patients. Initiatives to educate neurologists on the benefits and availability of non-terminal specialist palliative services could potentially improve patient access to this care.

Tables

Table 4.6 Demographic Characteristics of Physician Participants (N=62)

Characteristic	**M**	**SD**
Age (years)	45.8	10.4
Length of time as physician (years)	15.4	10.3
Length of time working with PD patients	14.3	9.3
Complementary clinicians in practice	2.2	1.7
Endorsed Costs	2.1	0.3
Endorsed Rewards	3.3	0.4
	N	**%**
Sex		
Male	36	60%
Female	24	40%
Movement Disorders Specialist		
Yes	55	91.7%
No	5	8.3%
Refer to Non-terminal Palliative Care		
Yes	32	54.2%
No	27	45.8%

Table 4.7 Kruskal-Wallis Bivariate Analyses Examining Mean Number of Palliative Referrals by Agreement with Each SET Item

Item	Strongly Agree	Agree	Disagree	Strongly Disagree	x^2	p
Reward Statements						
1. This service could render improved patient symptoms/outcomes	6.09 (11.88)	2.19 (2.48)	.	.	0.02	0.90
2. Interdisciplinary team care provided by palliative care is beneficial for PD patients	5.33 (10.75)	2.29 (2.71)	0 (0)	.	0.97	0.62
5. PD patients would benefit from biopsychosocial treatment of symptoms	4.68 (9.82)	3.88 (8.23)	.	.	0.04	0.85
8. The service may improve patient/family satisfaction	6.76 (12.23)	1.77 (2.47)	3.33 (5.77)	.	1.95	0.38
10. I have had previous positive experiences with palliative care	8.91 (13.54)	1.81 (2.21)	0 (0)	.	8.52	0.01
11. Palliative care may be able to meet patient needs that I cannot address	6.97 (11.99)	1.59 (2.39)	0 (0)	.	5.18	0.08
13. Palliative care could lead to improved patient care coordination between practitioners	14.00 (16.55)	1.45 (2.14)	4.33 (4.59)	.	12.27	0.002
15. Palliative care services could lighten my workload	9.36 (11.73)	1.56 (2.34)	6.80 (15.30)	.	7.25	0.03
18. My patients have had previous positive experiences with palliative care	15.75 (18.56)	3.37 (5.50)	0.57 (1.09)	0 (0)	15.17	0.002
Cost Statements						
3. It is uncomfortable to discuss palliative care with patients	4.25 (4.19)	2.84 (8.86)	4.48 (10.44)	7.33 (7.60)	8.60	0.04
4. A palliative referral could lead to a loss of my autonomy in patient care	2.67 (4.62)	4.00 (4.24)	1.92 (2.64)	11.92 (16.87)	3.74	0.29
6. Outpatient and/or non-terminal palliative programs are not available	0.86 (1.46)	1.43 (2.79)	5.63 (9.11)	21.33 (25.01)	14.43	0.002
7. A palliative referral may lead to potential communication issues between practitioners	14.00 (15.56)	1.55 (2.40)	3.84 (8.25)	10.44 (16.02)	8.24	0.04
9. Non-terminal palliative care is inappropriate for PD patients	12.5 (10.61)	3.50 (0.71)	2.67 (7.08)	6.29 (11.68)	7.04	0.07
12. PD patients would not be interested in palliative care	.	2.90 (3.98)	3.68 (8.87)	8.30 (12.91)	0.63	0.73
14. I am unaware of non-terminal palliative care	3.25 (4.72)	0.30 (0.95)	1.50 (1.91)	10.00 (13.74)	17.09	0.0007
16. Palliative care cannot meet any patient needs that I cannot address directly	0 (0)	3.40 (4.10)	2.18 (3.95)	11.54 (16.35)	8.92	0.03
17. Palliative care is already provided to my patients by me	24.80 (19.63)	3.39 (5.59)	1.52 (2.40)	2.40 (3.58)	13.31	0.004

Table 4.8 Poisson Regression Analysis Summary for Pro and Con Endorsement Predicting Palliative Referral

	Full Model				**Reduced Model**			
Variable	***B***	***Se B***	***t***	***p***	***B***	***Se B***	***t***	***p***
Predictor Variable								
Pro Statements	2.52	0.36	48.50	<0.0001	1.81	0.25	51.00	<0.0001
Con Statements	-0.90	0.34	7.02	0.008	-1.41	0.26	30.56	<0.0001
Covariates								
Physician Type (Movement Specialist)	1.05	0.49	4.56	0.03	1.40	0.46	9.24	0.002
Number of Clinicians	0.13	0.04	8.84	0.003	0.08	0.03	5.12	0.02
Age	-0.07	0.03	6.93	0.009				
Yrs in Practice	0.02	0.02	0.56	0.46				
Yrs Working with PD Pts	0.07	0.03	5.39	0.02				
Sex (Male)	0.13	0.16	0.65	0.42				

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CHAPTER 6

ADDITIONAL RESULTS

Additional results from the study, which are not described in the preceding manuscripts are presented in the following section.

Aim 1

Overall the level of reported palliative need is relatively low; however, the qualitative results (see Manuscript 1) have indicated that this may be due to patients generally believing their physician was a resource for medications alone rather than any other resources [Table 4.9].

Response categories for the degree of need were collapsed into ‘addressed’ and ‘unaddressed’ categories. Chi-square tests were run in each symptom group to examine the proportion of met vs. unmet need. Physician type (e.g., primary care, general neurologist, specialist) was found to be significantly related to the proportion of addressed and unaddressed need in all symptom/need items with the exception of fatigue and spiritual need [Tables 4.10-4.14].

Post hoc t-tests were run for each participant group between symptom categories to determine whether there were significant differences between types of need. For patients, significant differences were found between the following categories: physical need was greater than financial need (t (48) = 2.59, p=0.01); psychological need was greater than social need (t (48) = 3.03, p = 0.004); psychological need was greater than financial need (t (48) = 4.32, p<0.0001), and psychological need was greater than spiritual need, (t (48) = 2.19, p= 0.03). Physicians reported their patients having significant differences in need between the following categories: physical need was greater than social need (t (64) = 2.14, *p* = 0.04); physical need was less than spiritual need (t (64) = -2.23, *p*= 0.03); psychological need was less than spiritual need (t (64) = -3.26, 0.002); social need was less than spiritual need (t (64) = -3.62, 0.0006); and financial need was less than spiritual need (t (64) = -3.04, *p* = 0.003) [Tables 4.15-4.24]. Although these differences were found to be statistically significant, some of these differences may so small that they may not be clinically meaningful.

Aim 2

The qualitative arm of this study also aimed to examine palliative need for PD patients with respect to the Social Ecological Framework (SEF). As themes emerged in analysis and were coded in transcripts, they were categorized by level of the SEF. There was significant overlap for patients between the community and institutional levels, so these were combined, resulting in intrapersonal, interpersonal, community/institutional, and policy factors that influence health [Figures 4.1 and 4.2].

Numerous relationships were found between factors in each level of the framework, as evidenced by Figure 4.2. The lines connecting each theme represent an overlap in coding, which indicated a relationship between the two factors. For instance, one patient discussed race in terms of her support system. She had difficulty locating other African American females with PD, and as a result, she felt like her support system was lacking in some way. Race was also related to patient education because she said she initially believed that PD was a “white person’s disease” and, therefore, she could not have it.

Moderating factors, which transcended categorization into the SEF, were also noted in analysis. These moderating themes included: Education, Care Coordination, and Access to Care. The availability and quality of these moderating factors appeared to affect the strength of positive outcomes to some degree. For example, education pertained to the need for information about the disease; information on classes and support programs for patients and families; and guidance regarding the role that other specialists and therapists may play in the treatment of symptoms and needs. This last component of education directly related to Access to Care. Without education on the services that other providers may offer to help manage the disease, patients' access to these care options was limited.

Substantial research has been devoted to the importance of education and access to care (Montgomery, Lieberman, Singh, & Fries, 1994; Prizer & Browner, 2012; Shimbo et al., 2004). Care coordination, however, is a less-researched factor, which did appear to moderate the quality of care patients could receive. Because of the complex needs of PD patients, they typically require numerous clinicians for optimal manage of the disease (Golden, Lavender, & Metzer, 1989; Prizer & Browner, 2012). Additionally, most patients interviewed were also coping with co-occurring medical conditions, which at times necessitated surgical intervention. In some acute cases, care was coordinated well for the patient; however, this coordination was inconsistent and at times resulted in complications for the patient. Additionally, due to a lack of communication between physicians, some patients experienced clinical issues resulting from a lack of knowledge that their other physicians may have about PD. One male participant noted, "*...My GP keeps saying, "That's not Parkinson's. That's your old age creeping up on you." I think he's probably of the school that Parkinson's means tremors and that it doesn't affect everything else in your body.*" While substantial research examines the importance of patient-provider communication as well, one interesting finding, although only reported by two participants, also deserves additional research and attention. While most patients try to present all of their symptoms and needs to physicians during their appointments, these two participants noted the desire to appear as they were doing well to their neurologist. By appearing to be doing better than they were, they might receive a more positive report from the physician, and this seemed to affect psychological coping of the illness through the denial of reality. One patient in his 40's noted, "*On one hand you want to look like you're doing good for your doctor, and if he doesn't see that you're doing worse, you can pretend that you're not doing worse. And it's like this little game. And then if he doesn't know, he can't help you."* When asked how neurology appointments typically go, another patient's wife responded, "*Pretty much the doctor asks him when he comes in 'well how are you doing? Need anything? Let me watch you walk.' You know it's that kind of thing..." [Patient]: "Course I do my best to put on a good show when I go see him."*

At the intrapersonal level of the framework, the most prominent themes that emerged were patient symptoms and needs, income, and race. The relationship of race in the SEF model has been discussed previously. Patient symptoms related to communication as appropriate communication of needs to the physician often moderated the resulting care coordination, education the patient received, and access to other clinicians. Patient income was often tied to their ability to continue working after the diagnosis, and it influenced their insurance coverage, their long-term care resources, and ultimately their access to care in general as well. One participant, who reported some financial need, noted while discussing therapies and long-term care planning options, "*I met a lot of the service providers…and it's a business. I mean, if you don't have financial resources, there's not that much available."*

At the interpersonal level of the framework, the most prominent emergent themes were relationship status, support systems, the neurologist, other clinicians, and work. The importance of support systems, the neurologist, and work as it pertains to income in PD management are relatively clear; however, some interesting new findings emerged regarding relationship status.

Many participants noted the importance of a spouse in managing care and needs. Conversely, the single patients who participated in this study noted some of the challenges that they encounter, including how very little literature and few programs target the needs of single individuals. One woman in her 60’s noted, “*For me, the big thing is being a single person. I don't have a caregiver. And all the literature, ADPA and everybody else, is treating the family…And that model doesn't work for me.”* A younger participant in his 40’s discussed how social stigma pertaining to PD affected his dating life, “*...So I think for me one of the biggest challenges is in the sphere of dating. You know...probably would have rather told someone I had VD or something. But um...that would actually be a good way to break the Parkinson's. I got herpes, no just kidding, it's Parkinson's [laughter].. . So you know that's been the hardest part.”* It was also noted how having a carepartner could ensure that physicians have a more comprehensive understanding of symptoms and needs, and the care single individuals receive may differ as a result, as one participant stated, “*…Yea I bought a house in Mississippi in an auction on kind of an impulsive thing and bought a bunch of memorabilia from Graceland, and you know, overspend what I shoud've...If you're having compulsive behaviors, it's hard to give them up or, at the risk of...I can feel worse and not do stupid shit, or I can do stupid shit and feel better...I suppose that's when it's good to have a spouse for somebody to step in and say, "You're changing something."”*

At the institutional and community levels of the SEF, the social response to PD, support groups, classes and therapies, long term care resources, and the healthcare system in general were noted as important factors in care. Regarding social response, one woman found that discussing her PD could make others uncomfortable, *“ I didn’t know, especially at work, that you didn’t tell everybody right away. And then I realized that some people don’t handle that very* *well. So I tried to be more cautious about sharing information.”* Another participant found that his PD symptoms could be misleading to friends, *“I have a friend who’s suggested I might be depressed, but I think he’s just not used to the masked face and doesn’t understand that the quietness is from the speech issues.”*

Regarding classes and therapies, one male participant discussed the local PD Gladiators program, “*The mission is to spread the word about exercise and the better methods on Parkinson’s disease, and also make community-based group exercise programs available to people with Parkinson’s.”* A female participant who was managing well with her PD noted, “*Roswell has a great recreation department, so I participate in a lot of classes there. And they’ve actually got one for Parkinson’s that’s specific for people with Parkinson’s which has been great.”*

Lastly, at the policy level, insurance, social security, and the disability program were factors that played a major role in the quality of care a patient could receive in PD management. While the majority of study patients reported having very comprehensive insurance coverage, one participant, who was covered by an HMO, stated that she had significant issues in accessing physicians and receiving high quality ongoing care for her disease, “*The main headache I have …is I have to have a referral to see anyone other than my primary care physician.”*

Tables

Table 4.9 Mean levels of need as reported by patients and physicians

Symptom or Need	Patients M(SD)	Physicians M(SD)
Tremor	1.3 (0.6)	1.6 (0.5)
Balance issues (no falls)	1.9 (0.9)	2.0 (0.7)
Balance issues (falls)	2.0 (0.8)	2.5 (0.9)
Freezing of gait	2.1 (0.9)	2.7 (1.0)
Activities of daily living	1.9 (0.9)	2.1 (0.7)
Memory	1.9 (1.0)	2.5 (0.9)
Swallowing issues	1.8 (0.9)	2.2 (0.8)
Incontinence	2.0 (9.1)	2.4 (0.8)
Pain	1.8 (0.9)	2.2 (0.8)
Fatigue	2.2 (1.0)	2.6 (0.8)
Constipation	2.0 (0.8)	1.8 (0.7)
Emotion impact of dx	1.9 (0.8)	1.8 (0.5)
Mood	1.9 (0.9)	2.0 (0.5)
Distress	1.8 (0.9)	2.2 (0.7)
Frustration	1.9 (0.9)	2.3 (0.7)
Cognition	2.0 (1.0)	2.5 (0.9)
Verbal communication	1.8 (0.9)	2.0 (0.6)
Physical communication	1.9 (0.9)	2.1 (0.6)
Family needs	2.0 (1.0)	1.9 (0.6)
Assistive tech. needs	2.0 (1.1)	2.1 (0.8)
Community resources	1.9 (1.2)	1.9 (0.7)
Advance care planning	2.3 (1.2)	2.2 (0.7)
Respite needs	2.0 (1.1)	2.5 (0.8)
Caregiver needs	1.8 (1.1)	2.2 (0.8)
Care coordination	2.1 (1.1)	2.0 (0.7)
Long term care needs	2.6 (1.1)	2.2 (0.8)
Job needs	2.2 (1.2)	1.9 (0.7)
Disability needs	2.2 (1.2)	2.0 (0.7)
Paying for rehabilitation	2.3 (1.2)	2.3 (0.8)
Paying for respite	2.8 (1.2)	2.6 (1.0)
Spiritual needs	2.3 (1.2)	2.7 (0.4)

Table 4.10 Proportion of Addressed Physical Symptoms/Needs by Physician Type*

	No Physician		**Primary Care Physician**		**General Neurologist**		**Movement Disorders Specialist**			
	n	%	n	%	n	%	n	%	X^2	p
Tremor	0	0.0	0	0.0	15	30.6	23	46.9	50.5	<0.0001
Balance issues (no falls)	0	0.0	0	0.0	13	26.5	14	28.6	45.6	<0.0001
Balance issues (falls)	2	4.1	0	0.0	5	10.2	12	24.5	46.3	<0.0001
Freezing of gait	1	2.0	0	0.0	4	8.1	16	32.7	62.7	<0.0001
Activities of daily living	6	12.2	3	6.1	7	14.3	10	20.4	49.3	<0.0001
Memory	7	14.3	1	2.0	6	12.2	11	22.5	46.6	<0.0001
Swallowing issues	4	8.2	2	4.1	7	14.3	11	22.5	53.7	<0.0001
Incontinence	12	24.5	2	4.1	4	8.2	5	10.2	49.5	<0.0001
Pain	4	8.2	4	8.2	4	8.2	12	24.5	50.7	<0.0001
Fatigue	4	8.2	2	4.1	6	12.2	17	34.7	5.1	0.2728
Constipation	7	14.3	8	16.3	4	8.2	10	20.4	53.9	<0.0001

* The n for each may vary based on the number of people who responded to the item.

Table 4.11 Proportion of Addressed Psychological Symptoms/Needs by Physician Type*

	No Physician		**Primary Care Physician**		**General Neurologist**		**Movement Disorders Specialist**			
	n	%	n	%	n	%	n	%	X^2	p
Emotion at diagnosis	5	10.2	3	6.1	9	18.4	13	26.5	41.8	<0.0001
Mood	7	14.3	3	6.1	7	14.3	11	22.5	40.5	<0.0001
Distress	10	20.4	1	2.0	8	16.3	8	16.3	49.7	<0.0001
Frustration	12	24.5	2	4.1	7	14.3	8	16.3	39.0	<0.0001
Cognition/Confusion	7	14.3	0	0.0	4	8.2	8	16.3	47.8	<0.0001

* The n for each may vary based on the number of people who responded to the item.

Table 4.12 Proportion of Addressed Social Needs by Physician Type*

	No Physician		**Primary Care Physician**		**General Neurologist**		**Movement Disorders Specialist**			
	n	%	n	%	n	%	n	%	X^2	p
Verbal Communication	11	22.5	3	6.1	6	12.2	6	12.2	43.0	<0.0001
Physical Communication	10	20.4	0	0.0	4	8.2	12	24.5	50.3	<0.0001
Family Needs	9	18.4	5	10.2	3	6.1	5	18.4	51.3	<0.0001
Assistive Technology	4	8.2	5	10.2	6	12.2	5	10.2	56.4	<0.0001
Resource Needs	11	22.5	1	2.0	5	10.2	6	12.2	45.1	<0.0001
Advance Care Planning	7	14.3	3	6.1	3	6.1	2	4.1	53.8	<0.0001
Respite	7	14.3	1	2.0	1	2.0	2	4.1	38.1	<0.0001
Caregiver Needs	15	30.6	1	2.0	0	0.0	4	8.2	47.2	<0.0001
Care Coordination	5	10.2	4	8.2	3	6.1	4	8.2	49.1	<0.0001
Long Term Care Planning	3	6.1	0	0.0	0	0.0	2	4.1	44.7	<0.0001

* The n for each may vary based on the number of people who responded to the item.

Table 4.13 Proportion of Addressed Financial Needs by Physician Type*

	No Physician		Primary Care Physician		General Neurologist		Movement Disorders Specialist			
	n	%	n	%	n	%	n	%	X^2	p
Job	1	2.0	2	4.1	3	6.1	3	6.1	56.3	<0.0001
Disability Needs	4	8.2	1	2.0	7	14.3	5	10.2	54.3	<0.0001
Paying for Rehabilitation	7	14.3	2	4.1	1	2.0	6	12.2	49.4	<0.0001
Paying for Respite	3	6.1	1	2.0	0	0.0	2	4.1	55.7	<0.0001

* The n for each may vary based on the number of people who responded to the item.

Table 4.14 Proportion of Addressed Spiritual Needs by Physician Type*

	No Physician		Primary Care Physician		General Neurologist		Movement Disorders Specialist			
	n	%	n	%	n	%	n	%	X^2	p
Spiritual Needs	8	34.8	1	4.4	1	4.4	2	8.7	1.4	0.717

* The n for each may vary based on the number of people who responded to the item.

Table 4.15 Post hoc t-tests between physical and psychological symptom category means.

	Physical Need		Psychological Need			
	M	SD	M	SD	t	p
Patients	1.38	0.76	1.48	0.99	-0.88	0.38
Physicians	2.24	0.55	2.15	0.52	1.64	0.11

Table 4.16 Post hoc t-tests between physical and social symptom category means.

	Physical Need		Social Need			
	M	SD	M	SD	t	p
Patients	1.38	0.76	1.19	1.03	1.74	0.09
Physicians	2.24	0.55	2.11	0.48	2.14	0.04

Table 4.17 Post hoc t-tests between physical and financial symptom category means.

	Physical Need		Financial Need			
	M	SD	M	SD	t	p
Patients	1.38	0.76	0.98	1.19	2.59	0.01
Physicians	2.24	0.55	2.21	0.59	0.39	0.70

Table 4.18 Post hoc t-tests between physical and spiritual symptom category means.

	Physical Need		Spiritual Need			
	M	SD	M	SD	t	p
Patients	1.38	0.76	1.06	1.39	1.53	0.13
Physicians	2.24	0.55	2.54	0.99	-2.23	0.03

Table 4.19 Post hoc t-tests between psychological and social symptom category means.

	Psychological Need		Social Need			
	M	SD	M	SD	t	p
Patients	1.48	0.99	1.19	1.03	3.03	0.004
Physicians	2.15	0.52	2.11	0.48	0.78	0.44

Table 4.20 Post hoc t-tests between psychological and financial symptom category means.

	Psychological Need		Financial Need			
	M	SD	M	SD	t	p
Patients	1.48	0.99	0.98	1.19	4.32	<0.0001
Physicians	2.15	0.52	2.21	0.59	-0.78	0.44

Table 4.21 Post hoc t-tests between psychological and spiritual symptom category means.

	Psychological Need		Spiritual Need			
	M	SD	M	SD	t	p
Patients	1.48	0.99	1.06	1.39	2.19	0.03
Physicians	2.15	0.52	2.54	0.99	-3.26	0.002

Table 4.22 Post hoc t-tests between social and financial symptom category means.

	Social Need		Financial Need			
	M	SD	M	SD	t	p
Patients	1.19	1.03	0.98	1.19	1.48	0.14
Physicians	2.11	0.48	2.21	0.59	-1.33	0.19

Table 4.23 Post hoc t-tests between social and spiritual symptom category means.

	Social Need		Spiritual Need			
	M	SD	M	SD	t	p
Patients	1.19	1.03	1.06	1.39	0.64	0.52
Physicians	2.11	0.48	2.54	0.99	-3.62	0.0006

Table 4.24 Post hoc t-tests between financial and spiritual symptom category means.

	Financial Need		Spiritual Need			
	M	SD	M	SD	t	p
Patients	0.98	1.19	1.06	1.39	-0.40	0.69
Physicians	2.21	0.59	2.54	0.99	-3.04	0.003

Figures

Figure 4.1 Prominent Social Ecological Themes in the Palliative Needs and Care of PD patients

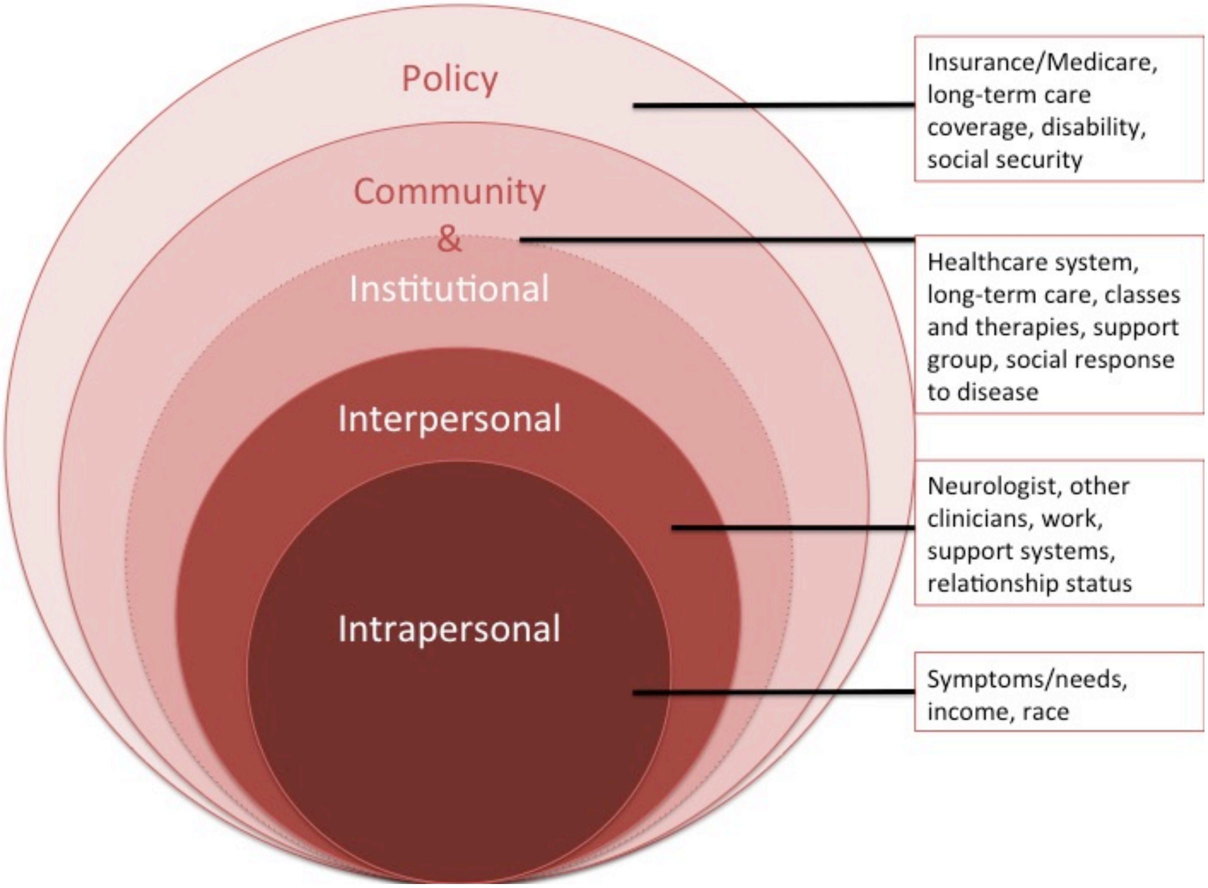
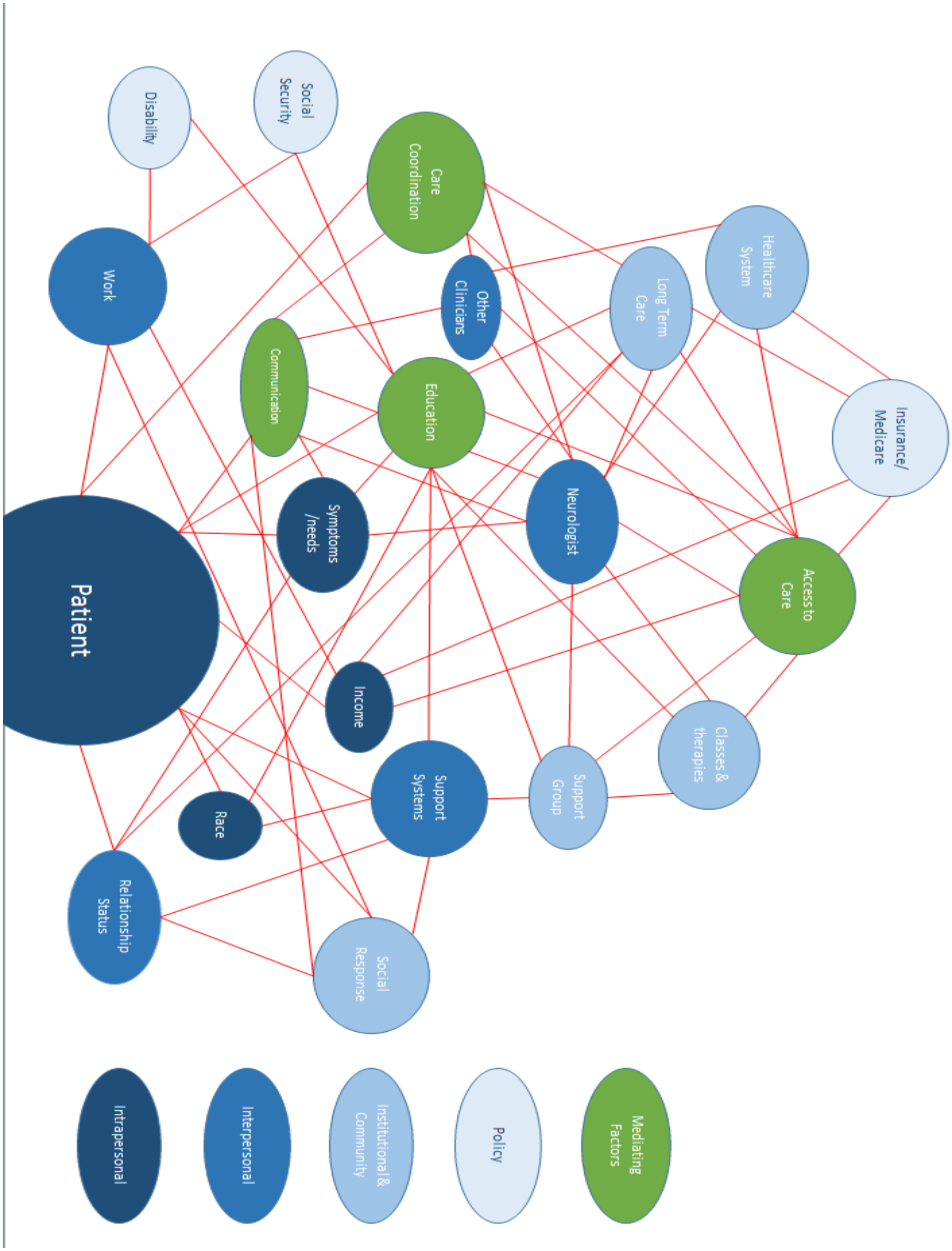


Figure 4.2 Interconnections of Factors within the Social Ecological Framework of Needs and Care in Parkinson's Disease



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CHAPTER 7

DISCUSSION

The complex nature of PD requires ongoing interdisciplinary care throughout the course of the disease, and a palliative approach is commonly advocated for this population (Bunting-Perry, 2006; Miyasaki, 2013; Prizer & Browner, 2012). However, a majority of individuals with PD do not receive specialist palliative care until the end of life (American Academy of Humanities, 1996; Centers for Medicare & Medicaid Services, 2009; Kutner et al., 2002). The purpose of this mixed methods study was to determine the unmet palliative needs of PD patients throughout the disease and to understand patient- and provider-based barriers and facilitators of palliative services use.

Aim 1

The results of this study provide empirical evidence to support the role of palliative care in the treatment of PD patients, and numerous symptoms, particularly non-physical needs, may be more difficult for neurologists to address. In this study, although both patients and physicians reported palliative need, patients reported lower need on the survey than physicians did. The qualitative results of Aim 2, however, indicated that this may be a conservative estimate of need. One critical finding was the disagreement between patients and neurologists regarding unmet palliative needs. These results emphasize the unique manifestation of PD symptoms for each patient, as well as the differing levels of patient involvement in seeking resources independently to address needs (Prizer & Browner, 2012). Additionally, neurologists may have varying levels of interdisciplinary support and/or comfort in addressing palliative symptoms and needs. A separate study, focusing on end-of-life care, also noted disagreement between patients and physicians regarding needs and preferences in care (Steinhauser et al., 2000). These findings underscore the individuality of treatment of PD patients and the importance of communication between neurologists and their patients to assess patient-identified needs and clinical priorities in care.

The results of this study also indicate that there are numerous opportunities for the integration of outpatient non-terminal palliative care in the long-term care of PD patients. Depending on the specialization and resources of the neurologist, outpatient palliative care could complement neurological care early in the course of the disease, on a more limited basis, by providing psychosocial support and addressing the educational needs of patients. As the care coordination needs of patients increase over time, palliative care could assist in this coordination and may be well-positioned to facilitate communication between providers involved in the patient’s care. Chaplains on the palliative team could address the religious and spiritual coping of the disease and symptoms for the patient and provide spiritual support in care. In later stages of the disease, palliative teams may be able to assist in managing some emerging physical symptoms, such as pain and constipation. While some of these symptoms have been described in terms of disease stage in previous literature (Bunting-Perry, 2006; Hudson et al., 2006), the present study’s findings underscore the importance of patient-centered participatory decision making in ongoing PD treatment. The resources of the neurologist as well as individual needs of the patient may require differing levels of palliative intervention at varying points of the illness.

Aim 2

Although Aim 1 survey results indicated some disagreement between neurologists and patients regarding palliative need, a possible explanation for this finding is that, in the qualitative arm of the study, many patients indicated that they see their neurologists for medication management only and do not recognize that physicians and their teams may be useful in providing educational information, access to care, and information on community and financial resources to manage chronic illness. Subsequently, most patients report turning to the internet and their support systems to address these needs. While self-advocacy is a crucial factor in the optimal management of chronic diseases, such as PD, a collaborative partnership between an invested provider and informed patient would render the best outcomes for patient care (van der Eijk, Faber, Shamma, Munneke, & Bloem, 2011b). The holistic and integrative approach of palliative care can help support neurologists in these efforts, by supplementing standard neurology care and addressing the psychosocial needs of patients in particular.

The findings in this Aim also highlighted several gaps in standard care: lack of healthcare education and the need for more effective care coordination. Numerous participants noted that they received very little educational information directly from neurologists, and most patients located information on the disease, treatments, programs, and resources from the internet or from support groups. A separate study found similar themes related to a patient-centered approach in PD, where patients expressed the need for tailored information from their physicians regarding education, treatment options, and programs and therapies to manage symptoms (van der Eijk et al., 2011a). The importance of care coordination in PD treatment has been emphasized in previous research as one of the highest ranked indicators of the quality of care (Cheng et al., 2004).

Additional factors that emerged as having important implications for patients’ HRQoL included the importance of support groups and the vital role of spirituality and religion in coping. Previous research has indicated that support groups can aid individuals with PD in effective management of the disease (Charlton & Barrow, 2002). Another study has also noted the importance of spirituality in health maintenance, finding that although patients do not necessarily expect physicians to discuss spirituality, they want to be asked about coping and support strategies, including those related to spiritual health (Hebert et al., 2001). These results provide insight into opportunities for palliative intervention, particularly with regard to patient education, care and resource coordination, and the spiritual support and intervention of palliative care chaplains.

Another interesting finding in need of additional research is the tendency of some patients to under-report symptoms in order to 'look good' for the neurologist. Although somewhat rare, this coping strategy may negatively affect the quality of care the patient receives. While a separate study has noted gender differences in patient reports of symptoms to physicians (Kroenke & Spitzer, 1998), no other study was identified that had found a similar sentiment of trying to 'look good' for a physician's evaluation. With a greater understanding of this coping style, clinicians may be able to better identify it in clinic and encourage the patient to provide a more objective report of symptoms and needs.

Aim 3

This study is unique in that it examined neurologist-related barriers and facilitators to referral to outpatient palliative care services. Because of the limited understanding most patients have of non-terminal palliative care, neurologists have substantial control over patient access to these services. Understanding of the perceived costs and rewards of palliative care referral can help with future efforts to better integrate palliative services into the long-term care of PD patients.

Although neurologists endorsed more rewards than costs to referral, only a slight majority reported actually referring PD patients to non-terminal palliative care. Additionally, of those who do refer, the average annual number of patients referred was 4.34. This may be suggestive, to some extent, of the limited geographic availability of specialist non-terminal palliative care services (Glass & Burgess, 2011; Meier & Beresford, 2008; Morrison et al., 2005). Also, neurologists' opinions may differ regarding what constitutes a PD patient most appropriate for a palliative referral. Although the Institute of Medicine recommends patients with serious illness have access to palliative care, even early in the course of illness, many physicians may still equivocate palliative care with strictly end-of-life care (Dalal et al., 2011), and therefore, timely referrals may be postponed. The National Parkinson Foundation has indicated that PD patients are appropriate for palliative care if they have a Hoehn and Yahr stage 3 or above or if dementia, psychosis, or caregiver strain is present (Miyasaki, 2013). However this study found that many patients may have palliative needs earlier on in the disease course that may benefit from treatment, such as psychological symptoms, educational needs, and care coordination assistance. These findings indicate the need for neurologists to have a thorough understanding of the benefits of palliative care at all disease stages in order to determine on an individual basis which patients are most appropriate for the service.

Limitations

There are several limitations to the present study. Because patients were recruited from support groups sampling bias may be an issue. Specifically, these patients are likely better informed of resources and may have higher levels of support than the general PD population. A previous study has found that PD patients attending support groups are more likely to be seeing a movement disorders specialist; to have postgraduate education; and to have Medicare coverage

(Dorsey et al., 2010). These factors may also contribute to sampling bias, as these patients may receive better quality care and have greater knowledge of and access to treatments and resources than the general PD population. This possible sampling bias may have resulted in more conservative estimates of palliative needs than the general PD patient population, including those without support group access, may have more limited support and knowledge of treatments and care. Despite this potential bias, the participants still noted numerous palliative needs. This may indicate that patients in areas with more limited access to support groups, specialists, classes and therapies, may have greater levels of unmet palliative need.

Similarly neurologists were recruited primarily from specialist organizations. In particular, the National Parkinson Foundation's criteria for movement disorders center inclusion in their centers of excellence network include meeting rigorous standards in clinical care, research, and patient education. Subsequently, these physicians may have enhanced access to interdisciplinary team care than most neurologists. Regardless of the possible sampling bias, the physician respondents still noted palliative need in all five domains of care. This may indicate that neurologists without specialization in movement disorders or without access to the clinical resources common to NPF centers of excellence may be more limited in their ability to address the palliative symptoms and needs of patients. This sampling bias may have also limited Aim 3 results, as the National Parkinson Foundation's commitment to palliative research may positively bias neurologists in their perceptions of palliative care as well as in their resulting referral practices.

The self-report nature of the survey may lead to inaccuracies due to recall bias; however, similar surveys exist and have been used in research to assess patient symptoms and physician referrals to palliative care (Ahluwalia & Fried, 2009; Jenkinson, Fitzpatrick, Peto, Greenhall, &

Hyman, 1997). Despite this, many of the variables in the study were perceptions of need, which are more challenging to measure in more objective ways. This study is also limited in that it is largely an exploratory study. However, the evidence in the field is still extremely limited, and a more thorough estimate and understanding of the palliative needs of PD patients was necessary to determine how neurologists and palliative care professionals can best collaborate in the complementary management of these complex patients.

Another possible limitation of the study is that the sample sizes for the quantitative survey were relatively small. They were appropriate for the exploratory nature of the study, and power analyses determined that these sample sizes were sufficient to detect a small effect size with an alpha of 0.05 and a power of 0.80 (Faul et al., 2009; Faul et al., 2007; Peto et al., 2001). However a larger sample could render more representative study results. The low Cronbach's alpha (0.37) for the group of cost statements may also limit the study; however removal of cost items did not improve reliability. Literature also supports the potential costs of palliative care used in the study (Ahluwalia & Fried, 2009; Bestall et al., 2004; Broom et al., 2012; Forrest et al., 2000; Kinchen et al., 2004; Shaw, 2010; Shortell, 1974; Shortell & Anderson, 1971; Walshe et al., 2008). However, future refinement of the survey is needed to improve reliability.

Strengths

While the palliative care of PD patients has been examined in prior literature (Bunting-Perry, 2006; Hudson et al., 2006), this is the first study to use a mixed methods approach. This study design enabled the examination of the research questions at hand from multiple perspectives, providing a more thorough and complete picture of the problem. Without the qualitative component of the study, the findings pertaining palliative need would have been very limited. The mixed methods design allowed for patient elaboration on palliative need, and exposed the presences of needs not indicated in the survey. Additionally, this study elicited responses from both patient and neurologist participants, allowing for a more comprehensive understanding of the extent of palliative need in this patient population.

Another strength of this study is that it applies the use of SET to physician referrals to palliative specialists. While SET has been used previously to examine physician referrals for consultative purposes (Shortell, 1974; Shortell & Anderson, 1971), no study has examined the referral practices of neurologists to palliative care. The results of this study contribute positively to the literature by providing an enhanced understanding of the referral practices of neurologists. These findings have the potential to be translated into interventions to affect clinical practice and improve overall patient care.

Future Directions

While a palliative approach is commonly advocated in the treatment of PD, little is known about the actual palliative need for patients that remains beyond standard neurological care. Additionally, research has not focused on the opportunity for palliative intervention prior to advanced stages of the disease. The present study can inform clinical practice by serving as a guide to the range of palliative needs that patients experience in the illness, and by providing insight into which needs are most commonly left unaddressed in standard care. The findings do, however, highlight the individuality of symptom manifestation as well as the varied ability of neurologists and their teams to manage more palliative needs. These results indicate the need for an individual approach to outpatient palliative consultation in PD care, based on the specific needs of the patient as well as on the skills and clinical staffing resources of the neurology team. Future studies should aim to examine the implementation of ongoing palliative care consultations to supplement standard neurological care. At least one Movement Disorders Center, operating in

Toronto, Ontario, Canada, has initiated this type of collaborative care for PD patients; however, further research is needed in order to understand the logistical challenges involved in the development and management of such a program. Future studies should focus on the feasibility of implementing such a program as well as the clinical effectiveness of outpatient palliative care services in this population.

This study also examined how neurologist-perceived costs and barriers of palliative care referral may affect referral practices. Significant barriers to referrals related to three primary themes: concerns about increased complications in managing PD patients alongside a palliative team, lack of knowledge about or availability of programs, and the perception that palliative needs were already well-addressed by the neurologist. Significant perceived rewards related to positive previous professional and patient-related experiences with palliative care as well as perception of improved coordination of patient care. These findings provide insight into opportunities for enhanced education for neurologists regarding the potential benefits of specialist, outpatient palliative care for PD patients. Future research should focus on the development and evaluation of provider-education programs to improve knowledge and understanding of the utility of this service for PD patients.

Conclusions

Because of the growing prevalence of Parkinson’s disease (PD) in the coming decades, it will become increasingly important to study and implement models of care that can best address the complex variety of symptoms of PD that may manifest throughout the longitudinal disease course (Kowal et al., 2013; Langston, 2006; Lees et al., 2009; Tolosa et al., 2006). This study contributes to a limited body of literature examining the palliative needs of PD patients, and it is unique in that it elicited responses from both PD patients and neurologists in practice. The findings indicate that there are unmet palliative needs experienced by PD patients, specifically regarding non-physical needs. Because of the interdisciplinary focus of palliative care, as well as the positive clinical outcomes that have been documented thus far for individuals with chronic and terminal illnesses (*Dying in America*, 2014; Morrison & Meier, 2004; Morrison et al., 2008; National Guideline Clearinghouse, 2013; Temel et al., 2010), a neurology collaboration with palliative care may most appropriately meet the patient needs identified in this study.

These results can inform collaborations between neurologists and palliative care professionals in the optimal management of PD patients by providing insight into which needs are most adequately addressed by standard neurological care and which are most often left unaddressed. Neurologists who are unsupported by interdisciplinary teams or who do not specialize in movement disorders may find that their patients benefit even more than patients of those who are better able to address palliative need. Because of the unique and individual manifestation of PD symptoms and the varying resources of practicing neurologists, a model of palliative care for PD depends on the balance between the individual needs of the patient and the resources and abilities of the neurologists. Periodic palliative consultations, which increase in frequency based on need, may be able to identify additional areas in which care, education, and treatment may be improved.

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APPENDICES

A. CAPACITY TO CONSENT FORM

Assess capacity to consent. Review the consent form with the participant and ask open ended questions about your study to determine comprehension. For example, “Can you tell me what will happen if you agree to take part in this study?”, “Do you have to be in this study?”, “Will this study help you?”, etc. As you review the consent information, determine if the participant meets the criteria below:

Please mark any of the following that apply:	**YES**
A. **The participant has the ability to communicate a yes or no decision.** This standard is applicable to all risk/benefit levels.	
B. **The participant has the ability to understand relevant information**; the person can tell you what the research procedures involve and what the consent information includes. This standard applies to all risk/benefit levels.	
C. **The participant has the ability to appreciate the situation and its likely consequences.** This standard applies to all research involving more than minimal risk.	
D. **The participant has the ability to manipulate information rationally.** This standard focuses on process, not outcome. For example, are decisions consistent with the religious, moral, and other beliefs of the person? This standard is critical for the most unfavorable risk/benefit levels.	

Step 3: Scoring the assessment. For all studies, you should answer “yes” to **A** and **B** in order for the participant to consent. If your study is above minimal risk (the level for potential harm is above what the participant would normally experience), you should also answer “yes” to **C** and **D**.

Step 4: Documenting the assessment. Use the following form to document your assessment based on the score in Step 3. If you marked A in Step 1, mark d in the form below:

I examined ________________(name) on _________(date) for the purpose of determining whether he/she is capable of un derstanding the purpose, nature, risks, benefits, and alternatives (including nonparticipation) of the research, making a decision about participation, and understanding that the decision about participation in the research will involve no penalty or loss of benefits to which the patient is otherwise entitled for the research project: (project title).

On the basis of this examination I have arrived at the conclusion that:

a. This participant has this capacity at this time ( )
b. There is a doubt about this participant’s capacity at this time and further evaluation is necessary ( )
c. This participant clearly lacks this capacity at this time and will need surrogate consent ( )
d. This participant already has a designated surrogate ( )

Signature of the evaluator:

Step 5: Include this form with the participant’s signed consent form (or signed surrogate form and participant’s assent form, where appropriate).

B. PALLIATIVE NEEDS IN PARKINSON'S DISEASE, PATIENT SURVEY

	How well do you feel each symptom is being managed by treatment from your clinician.					**Is this symptom being managed by treatment from your…**			
	Not Applicable (Don't have this symptom) 0	**Very Well** Symptom is not very bothersome 1	**Moderately Well** Symptom limits some activity or concentration 2	**Not Very Well** Symptom markedly affects activities or concentration 3	**Poorly** Symptom feels overwhelming 4	**Primary Care Physician**	**General Neurologist**	**Movement Disorders Specialist**	**None**
PHYSICAL									
1. Tremor									
2. Balance issues (no falls yet)									
3. Balance issues (falls)									
4. Freezing of gait									
5. Assistance with feeding, bathing, or dressing									
6. Memory issues									
7. Swallowing issues									
8. Incontinence									
9. Pain									
10. Fatigue									
11. Constipation									
PSYCHOLOGICAL									
1. Emotional impact of diagnosis									
2. Depression and/or anxiety									
3. Distress									
4. Frustration									
5. Confusion and/or cognitive impairment									
SOCIAL									
1. Verbal communication issues									
2. Physical communication issues (e.g., masked face)									
3. Family support needs									
4. Assistive technology needs									
5. Community resource needs (e.g., support groups, home health, etc)									
6. Advance care planning needs									
7. Respite									
8. Caregiver support									
9. Care coordination with providers									
10. Long-term care placement									
FINANCIAL									
1. Stopping employment									
2. Disability service needs									
3. Paying for rehabilitation/therapy									
4. Paying for respite needs									
SPIRITUAL									
1. Spiritual needs									

Please indicate your sex: Male Female **What is your age:** ___

What do you consider your race?

a) Black or African American
b) White or European American
c) Asian or Asian American
d) American Indian
e) Mixed or multiple races
f) Other ____________________________________

What is your approximate annual income before taxes?

a) Less than $15,000
b) $15,000-24,999
c) $25,000-34,999
d) $35,000-44,999
e) $45,000-54,999
f) $55,000-64,999
g) $65,000-74,999
h) $75,000-84,999
i) $85,000-94,999
j) $95,000 or more

For how many years have you been diagnosed with PD?___

Please check all of the following practitioners that you have been treated by for your PD:

___Nurse
___Social Worker
___Physical Therapist
___Occupational Therapist
___Speech and Language Pathologist
___Chaplain
___Palliative Care Specialist
___None of these

Have you been treated by a non-terminal palliative care team before? Yes or No

We would like to learn more about your experiences with Parkinson's disease through an interview. The interview will last approximately 1 to 1 ½ hours, and you will be compensated $20 for your time. The interview will be held at a time, date, and location convenient to you. You are not required to participate in the interview in order to complete this survey. If you would like to learn more about the interview or potentially participate, please provide your contact information in the space provided:

Name: ______________ Telephone: ______________ Email: _____________

C. PARKINSON'S DISEASE QUESTIONNAIRE – 39

Due to having Parkinson's disease, how often <u>during the last month</u> have you…	**Please tick <u>one</u> box for each question**				
	Never	**Occasion-ally**	**Some-times**	**Often**	**Always** or cannot do at all
Had difficulty doing the leisure activities which you would like to do?					
Had difficulty looking after your home, e.g. DIY, housework, cooking?					
Had difficulty carrying bags of shopping?					
Had problems walking half a mile?					
Had problems walking 100 yards?					
Had problems getting around the house as easily as you would like?					
Had difficulty getting around in public?					
Needed someone else to accompany you when you went out?					
Felt frightened or worried about falling over in public?					
Been confined to the house more than you would like?					
Had difficulty washing yourself?					
Had difficulty dressing yourself?					
Had problems doing up your shoe laces?					
Had problems writing clearly?					
Had difficulty cutting up your food?					
Had difficulty holding a drink without spilling it?					
Felt depressed?					
Felt isolated and lonely?					
Felt weepy or tearful?					
Felt angry or bitter?					
Felt anxious?					
Felt worried about your future?					
Felt you had to conceal your Parkinson's from people?					
Avoided situations which involve eating or drinking in public?					
Felt embarrassed in public due to having Parkinson's disease?					
Felt worried by other people's reaction to you?					
Had problems with your close personal relationships?					
Lacked support in the ways you need from your spouse or partner?					
Lacked support in the ways you need from your family or close friends?					
Unexpectedly fallen asleep during the day?					
Had problems with your concentration, e.g., when reading or watching TV?					
Felt your memory was bad?					
Had distressing dreams or hallucinations?					
Had difficulty with your speech?					
Felt unable to communicate with people properly?					
Felt ignored by people?					
Had painful muscle cramps or spasms?					
Had aches and pains in your joints or body?					
Felt unpleasantly hot or cold?					

D. PATIENT INTERVIEW GUIDE

PALLIATIVE NEEDS IN PARKINSON'S DISEASE

IN-DEPTH INTERVIEW GUIDE

PD PATIENT

Section I: Background information about the interview participant

I would like to begin by learning a little about you

Length of time in Atlanta

Educational background, type of occupation

  Social support available (i.e., family, friends, neighbors, etc)

Section II: Access to Care

Insurance coverage

  Any trouble paying for medical care

  If so, describe the situation

Describe the area in which you live

  Urban or rural

  Can you discuss the availability (are they present in the community) of community health resources

    In-home health

    Physical/occupational/speech therapy

    Senior centers

        Neurologists

        Mental health – Counselors, psychologists, social workers

    How close in proximity do you live to these resources

    Can you discuss whether or not you have access to these community health resources

        In-home health

        Physical/occupational/speech therapy

        Senior centers

        Neurologists

        Mental health – Counselors, psychologists, social workers

Section III: Individual's Diagnosis of Parkinson's Disease

Now I would like to ask a few questions about when you were first diagnosed with Parkinson's disease

Length of time with PD diagnosis [Prompt if needed: What year? How old were you?]

    Were you working?

        If so, what did you do?

        Did PD affect your work? How?

        Did you have to stop working?

First symptoms noticed prior to the diagnosis [Prompt if needed: rigidity, tremor, balance, slowness, sense of smell or taste, attention issues, etc]

    What age were you when you noticed these symptoms?

Discuss the appointment when your PD diagnosis was made

What was your reaction? [Prompt if needed: sadness, anger, relief, frustration, etc]

Did you have family with you? What family members?

If so, how did they react? [Prompt if needed: sadness, anger, relief, frustration, etc]

What types of information were you provided? [Prompt if needed: verbal, booklets, handouts, support group information, etc]

Do you feel you were provided enough information at that first appointment?

If not, what information do you wish you were provided?

What could have improved that appointment/experience?

When was medication initiated?

What medications?

Were symptoms well-managed?

Which ones?

For how long?

Were there any symptoms you wanted managed that were not addressed?

Describe the disease progression from diagnosis [Prompt if needed: What symptoms first occurred? How did symptoms build?]

In what disease stage (early, moderate, or severe) did different symptoms occur?

Section IV: Current PD Stage

In this next section, I want to get an idea of what your current symptoms and needs are

Please describe your current physical symptoms

Is the rigidity on one or both sides of your body?

Do your symptoms impair your ability to function?

Have you had any falls? Do you have any balance issues?

Do you need any assistance with standing, walking, feeding, bathing, or dressing?

How do you feel emotionally?

Any depression or anxiety?

Frustration?

Confusion or memory issues?

Have you had any social issues or needs?

Issues with communication?

Assistive technology?

Family dynamics?

Community resource needs?

Carepartner support?

Care coordination between physicians?

Have you experienced any financial difficulty?

Stopping employment?

Paying for medical care/therapies/etc?

Going on disability?

Have you experienced any spiritual issues or needs?

E. CLINICIAN SURVEY

How well do you feel you are managing these symptoms for a majority of your patients?

	Not Applicable (Most don't have this symptom) 0	**Very Well** (Able to address for most or all patients) 1	**Moderately Well** (Able to address for many patients) 2	**Not Very Well** (Have difficulty addressing for some patients) 3	**Poorly** (Have difficulty addressing for most patients) 4
PHYSICAL					
1. Tremor					
2. Balance issues (no falls yet)					
3. Balance issues (falls)					
4. Freezing of gait					
5. ADL assistance					
6. Cognitive issues					
7. Swallowing issues					
8. Incontinence					
9. Pain					
10. Fatigue					
11. Constipation					
PSYCHOLOGICAL					
1. Emotional impact of diagnosis					
2. Depression and/or anxiety					
3. Distress					
4. Frustration					
5. Confusion and/or cognitive impairment					
SOCIAL					
1. Verbal communication issues					
2. Physical communication issues (e.g., masked face)					
3. Family support needs					
4. Assistive technology needs					
5. Community resource needs (e.g., support groups, home health, etc)					
6. Advance care planning needs					
7. Respite					
8. Caregiver support					
9. Care coordination with providers					
10. Long-term care placement					
FINANCIAL					
1. Stopping employment					
2. Disability service needs					
3. Paying for rehabilitation/therapy					
4. Paying for respite needs					
SPIRITUAL					
1. Spiritual needs					

Sex: Male or Female

Age: ____

Do you specialize in Movement Disorders? Yes or No

Years in practice as a physician: ____

Years working with PD patients: ____

Have you referred any Parkinson's patients to non-terminal palliative care services? Yes or No

If yes, approximately how many patients have you referred to non-terminal palliative care over this past year?___

Have you referred any Parkinson's patients to hospice care services? Yes or No

If yes, approximately how many patients have you referred to hospice care over this past year?___

Have you referred any Parkinson's patients to an interdisciplinary team evaluation? Yes or No

If yes, approximately how many patients have you referred to an interdisciplinary team evaluation over this past year?___

Please check all of the following practitioners that work directly with you in your clinic.
___Nurse
___Social Worker
___Physical Therapist
___Occupational Therapist
___Speech and Language Pathologist
___Chaplain
___Palliative Care Specialist
___None of these

Please indicate your level of agreement with the following statements about non-terminal palliative care services.

		Strongly Agree	Agree	Disagree	Strongly Disagree
1.	The service could render improved patient symptoms/outcomes				
2.	Interdisciplinary team care provided by palliative care is beneficial for PD patients				
3.	It is uncomfortable to discuss palliative care with patients				
4.	A palliative referral could lead to a loss of autonomy in patient care				
5.	PD patients would benefit from biopsychosocial treatment of symptoms				
6.	Outpatient and/or non-terminal palliative programs are not available				
7.	A palliative referral may lead to potential communication issues between practitioners				
8.	The service may improve patient/family satisfaction				
9.	Non-terminal palliative care is inappropriate for PD patients				
10.	I have had previous positive experiences with palliative care				
11.	Palliative care may be able to meet patient needs that I cannot address				
12.	PD patients would not be interested in palliative care				
13.	Palliative care could lead to improved patient care coordination between practitioners				
14.	I am unaware of non-terminal palliative care				
15.	Palliative care services could lighten my workload				
16.	Palliative care cannot meet any patient needs that I cannot address				
17.	Palliative care is already provided to my patients by me				
18.	My patients have had previous positive experiences with palliative care				

F. INTERVIEW CODES

Background

- Education
- Family

Parkinson’s Disease

- Diagnosis
- Early stage
- Mid-stage
- Late stage
- Disease duration
- Affect on work
- Symptoms
  - Well-managed
  - Un-managed
  - Current
  - Tremor
  - Rigidity
  - Balance
  - Pain
  - Shortness of breath
  - Fatigue
  - Bowel or urination problems
  - Activities of daily living
- Current symptoms
- Appointment
  - Reaction
    - Sadness
    - Relief
    - Anger
    - Frustration
    - Disappointment
    - Surprise
- Information provided
  - Satisfactory
  - Unsatisfactory
- How to improve
- Medication
- Therapy

Other Concerns

- Financial difficulties
- Meals
- Getting medical care

Meaning behind illness
Adaptive equipment

Support from Physician/Clinic
Met needs
Unmet needs

Emotions
Happiness
Satisfaction
Distress
Frustration
Anxiety
Anger
Sadness
Punished
At peace

Palliative Care
Palliative care
Beneficial
Not beneficial
Accepting
Opposed
Previous experience
Family/friend previous experience
Physician referral
Hospice care
After explanation provided