

**A QUALITATIVE DESCRIPTION OF CARE PARTNER
EXPERIENCES AT THE PALLIATIVE AND THERAPEUTIC
HARMONIZATION (PATH) CLINIC**

by

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DEDICATION PAGE

I would like to dedicate this work to my family for their endless support and encouragement during the course of this degree. A special thank-you to my husband, Matthew, who knew never to ask, “When will you be done?”

I would also like to dedicate this work to my generous research participants. I am grateful for their time, honesty, and support of this research.

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ABSTRACT

Palliative and Therapeutic Harmonization (PATH) is a novel service providing care to frail, older adults facing complex medical and surgical decisions. This qualitative study examines the role PATH plays in the experience of the care partner attendee, who often acts as a surrogate decision-maker, in order to better appreciate which features are most beneficial and identify areas for program improvement. Semi-structured interviews were held with 13 individuals and analyzed using framework analysis. Themes emerged surrounding the referral process, emotionally challenging aspect of participation, and the outcome of self-efficacy. Care partners appreciate the information and support received, but require a greater understanding of the process prior to participation. After completing PATH, care partners of dementia patients perceive themselves as better able to cope in their role as a caregiver and surrogate decision-maker. Care partners appreciate having a continued connection to the clinic, including the support of PATH during the dying process.

LIST OF ABBREVIATIONS USED

PATH	Palliative and Therapeutic Harmonization Clinic
NSHA	Nova Scotia Health Authority
WHO	World Health Organization
NELS ICE	Network for End of Life Studies Interdisciplinary Capacity Enhancement
CHIPCS	Capital Health Integrated Palliative Care Service
GACC	Geriatric Ambulatory Care Clinic
CGA	Comprehensive Geriatric Assessment

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CHAPTER I. INTRODUCTION

Background

We are at the beginning of a seismic shift in the age distribution of the population in Canada. In 2005, approximately 13% of the population was aged 65 years or older, and this number is expected to grow to 25% by 2036 (Statistics Canada, 2006). This population shift has the potential to place extensive pressures on the current health care system. The assertion that the number of older adults will place unprecedented demand on the health care system is only partly right. In reality, it is the burden of multiple chronic diseases in this population that poses the most challenges to the way care is delivered (Corpus Sanchez, 2007; Murray & Lopez, 1997; Rapoport, Jacobs, Bell, & Klarenbach, 2004; Statistics Canada, 2006). Accumulation of health deficits (e.g., co-morbid disease, cognitive decline, lack of social support) results in a state of reduced resilience termed ‘frailty’ (Rockwood & Mitnitski, 2007). Frailty is an age-associated state that compromises one’s ability to withstand treatment and recover from injury or illness. The health care needs of frail older adults differ significantly from those of younger adults, including needs at end-of-life (Canadian Institute for Health Information, 2007; Evers, Meier, & Morrison, 2002; Statistics Canada, 2006). The health care system will need to modify its approach on providing care to address their needs in order to maintain sustainability. For this reason, studying alternative health service models for older adults approaching end-of life with multiple co-morbidities is of vital importance.

The Palliative and Therapeutic Harmonization (PATH) program was developed in response to the need for appropriate health care services for frail older adults. PATH is an innovative health service designed specifically for older adults with multiple co-morbidities (often including a diagnosis of dementia) who are nearing end-of-life (Mallery & Moorhouse, 2011; Moorhouse & Mallery, 2010).

The purpose of the PATH program is to provide a tailored balance of therapeutic (i.e. rehabilitative or curative) and palliative (e.g. symptom relief) care by taking into account the implications of frailty and cognitive impairment on outcomes associated with medical and surgical interventions, and ensuring palliative measures are appropriately timed. In addition to bringing frailty to the forefront of care, PATH differs from more specialized models of care in that it places great value on the active participation of family and other care providers (both informal and formal) and aims to empower patients and their care partners to make informed health care decisions in the future. Furthermore, unlike the palliative care paradigm, which evolved as a model for single system disease (e.g., cancer), PATH often serves as an early intervention program for frail older adults with multiple co-morbidities and competing causes for mortality. In this way, PATH can help patients and their families recognize frailty and terminal trajectories at an earlier stage, assist in the understanding of diagnoses and prognoses, encourage dialogue about goals of care, and enable patients and their families to avoid treatments and procedures that may compromise quality of life. With data indicating that approximately half of lifetime healthcare utilization occurs in the last six months of life (Alemayehu & Warner, 2004),

PATH was ultimately developed to facilitate appropriate health care planning that matches prognosis and aims to avoid ‘over-medicalization’ of the dying process.

PATH was introduced at the Nova Scotia Health Authority (NSHA) Central Zone (formerly Capital Health) in 2009. There is limited understanding of how the PATH process is received by patient and care partner participants, however participant’s informal responses have been positive. A preliminary analysis of feasibility and decision-making outcomes of the first 150 PATH patients has been conducted by the program developers (Moorhouse & Mallery, 2012). The outcomes from this study suggests that PATH may serve to improve care by assisting in decisions to avoid treatments and therapies that may not be appropriate for frail and/or cognitively impaired older adults. The majority of patients who complete PATH are unable to participate fully in care planning and decision-making discussions due to dementia or delirium. The PATH process purposefully involves care partners to both contribute information during a comprehensive assessment and to act as substitute decision makers during the care planning and decisions-making phase; therefore, the experience of the PATH care partner is of particular interest. Although much has been written about care partners and substitute decision-making, little is known about the care partners experience participating in decision-making, or acting as the surrogate decision maker during (and after) their time with the PATH program.

Through an exploration of the care partners experience with caring and making decisions for/with a PATH patient, and the role PATH has played in their experience, the PATH

program could be improved. Insights can be used to make certain that participants learn the best possible skills for handling the stresses and responsibilities associated with end-of-life care, and to ensure appropriate resources are allocated to the most beneficial aspects of PATH as future training materials and modifications for additional health care settings are developed.

Justification of Naturalistic Inquiry Approach

Prior to the initiation of this study (in 2011), insights into the participants experience at the PATH had been collected through a voluntary, anonymous, self-administered exit survey (not tested for reliability or validity) offered to the first n=60 participants to attend PATH in 2009-2010. The survey, which was designed to measure the extent to which they understood their own, or their family member's, medical health as well as their overall confidence in speaking with health professionals about health concerns was returned by 36 / 60 participants. In general, participants reported improved understanding and confidence, and though the process was found to be upsetting, satisfaction with the process was unanimous. Given the knowledge that respondents of satisfaction surveys tend to over-report positive experiences (Ingram & Chung, 1997), limited insights can be gleaned from this data.

A naturalistic inquiry approach was selected to provide further insight into participant experiences at PATH as it allows for a broad exploration of a variety of facets of subjective experience. A qualitative examination can potentially provide a rich depiction of the PATH process and its outcomes. This study employed an exploratory qualitative

approach to formulate a rich description and broad understanding of the PATH program from the care partners' perspective in order to gain insight into participant reactions to their experience with PATH, and how this experience impacted their role as a care provider for a frail, older adult nearing end-of-life. The qualitative description method, a form of naturalistic inquiry described by Sandelowski (2000, 2010), was selected based on its usefulness in tailoring clinical investigations, scales, needs assessments and questionnaires in mixed method and small independent research studies (Sullivan-Bolyai, Bova, & Harper, 2005).

Purpose

The purpose of this qualitative descriptive study was to explore care partners' experiences with PATH. The study generally aimed to answer the question, "What role does the PATH program play in the experience of a person caring for a frail, older adult diagnosed with multiple co-morbidities?"

Research Questions

The specific questions posed by this qualitative descriptive study are:

- 1 What tools and services do care partner attendees receive from PATH?
- 2 How do care partners perceive the PATH tools and services to have impacted their experiences with:
 - a discussions regarding end-of-life decision-making;
 - b stress and anxiety;
 - c care planning and provisions of care;

d access to services/resources?

- 3 Has the PATH experience had an effect on the care partners' perceived ability to manage end-of-life health care decisions (i.e., self-efficacy)?

CHAPTER II. LITERATURE REVIEW

Introduction

The purpose of this qualitative descriptive study was to explore the care partners' experience with the PATH Program, and the effect PATH has on their experience as a care provider for a frail, older adult with multiple, chronic, life-limiting conditions. This review of the literature provides the necessary context of the goals of end-of-life care programs and the services offered in NSHA Central Zone at the time the study participants attended PATH (2010 – 2011). A review of the unique health profile and care needs of frail older adults is provided, as well as a summary of the literature on health care decision-making, including proxy decision-making (required when a patient is cognitively impaired or otherwise incapacitated) and the experiences of those acting as surrogate decision makers.

End-of-life care

End-of-life care is a broad term encompassing the many types of care that can be received when a person has a terminal diagnosis or is expected to die in the near future (Canadian Institute for Health Information, 2011). The Senate of Canada has deemed that every individual “is entitled to access skilled, compassionate, and respectful care at the end of life” and should “die in relative comfort as free as possible from physical, emotional, psychosocial, and spiritual distress” (Carstairs & Beaudoin, 2000).

Specialized end-of-life care for terminally ill patients first emerged in the United Kingdom in the 1960s and 1970s as a result of the work of Dame Cicely Saunders

(Clarke, 2002). Dame Saunders launched the modern hospice movement, which focused on managing the symptoms and pain (emotional and physical) of terminally ill patients (rather than the curing of the underlying terminal illness). In 1967, Dame Saunders founded the first dedicated end-of-life-care facility, St. Christopher's House Hospice, in London, England.

In Canada, the first specialized end-of-life care services established were hospital-based; they emerged in the 1970s as means to meet the end-of-life needs of people with terminal cancer who were characteristically ill-informed about their diagnosis and prognosis (Brooksbank, 2009; Clarke, 2002). Without awareness of a terminal diagnosis, patients (and their families) had difficulty planning for, and experiencing, a comfortable death; pain medication was withheld and individuals routinely died with much suffering.

Balfour Mount, a physician at the Royal Victoria Hospital in Quebec, is credited with coining the term 'palliative care', often referred to as 'hospice palliative care' in Canada (Brooksbank, 2009). Palliative care has since been established as a discipline that should be offered to all Canadians diagnosed with a terminal illness.

The World Health Organization (WHO) defines palliative care as:

an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organization, 2017).

Palliative care often uses a team approach to address the care needs of both the patient and their family, and is applicable even in the early stages of life-threatening illness while therapeutic measures are being undertaken. Essentially, the goal of palliative care is to ensure those suffering from terminal illness, along with their families, are afforded the opportunity to experience a 'good death'. While the specific details differ for each individual, in general patients define a good death as being painless, anticipated, and not too burdensome on their family (Steinhauser et al., 2000a; Steinhauser et al., 2000b).

Despite the fact that palliative care has applicability to all terminally ill patients, few Canadians, and especially older adults with dementia, receive integrated, interdisciplinary palliative care aimed at alleviating physical, emotional, psychological and spiritual suffering at end-of-life (Canadian Institute for Health Information, 2007; Wilson, 2004). This lack of quality care can make a 'good death' a challenge to achieve within today's health care system; patients and their families routinely express dissatisfaction with care and services received towards the end-of- life (Carstairs & Beaudoin, 2000; Heyland et al., 2005). For example, local data reveals that family members of patients who died at the QEII Health Science Centre in Halifax find the experience stressful and traumatic (Workman & Mann, 2007). Family members reported not being prepared for death as an outcome, as well as having the perception that patients were not receiving palliative treatments in conjunction with therapeutic care. Data gathered in other centres shows that the degree to which family members feel unprepared is associated with the degree of stress and anxiety they experience at end-of-life (Hebert, Dang and Schulz, 2006).

End-of-life care in Nova Scotia

The province of Nova Scotia has the highest percentage of seniors in the country (Nova Scotia Department of Seniors, 2009) therefore, it follows that current and future demand for quality end-of-life care will be felt more strongly in this province (Statistics Canada, 2006). Between 1999 and 2004, over 27,000 Nova Scotians died as a result of seven major chronic diseases (i.e., cancer, diabetes mellitus, chronic ischemic heart disease, congestive heart failure, cerebrovascular disease (stroke), chronic obstructive pulmonary disease, and renal failure) (NELS ICE, 2008). Each of these individuals would have had a potential need for end-of-life health care services, such as general practitioner and specialist physicians, nursing care, hospital days, home care, specialized palliative care, long-term care, radiotherapy, medical oncology, and emergency services. Providing health care towards end-of-life is a costly and intensive obligation (Emanuel, 1996; Jakobson, Bergh & Ohlen, 2007). As an example, an Albertan study estimates the average cost of end-of-life care during the last 12 months of life for patients experiencing a sudden death to be approximately \$10,233 (Fassbender, Fainsinger, Carson & Finegan, 2009). This number rises to \$31,881 for patients with a terminal illness, \$36,652 for those with multiple co-morbidities/vulnerabilities, and up to \$39,947 for patients suffering from organ failure.

There are 10 palliative care programs in Nova Scotia that offer variable levels and types of services (Canadian Institute for Health Information, 2011; Lethbridge & Johnston, 2016; Nova Scotia Hospice Palliative Care Association, 2010). These programs developed independently, when the province (now under one Health Authority) consisted

of 9 District Health Authorities plus the Izaak Walton Killam Health Center for children and youth (Canadian Institute for Health Information, 2011; Lethbridge & Johnston, 2016). The types of services available include case management and assessment, pain and symptom management, volunteer support and bereavement services. Palliative care programs service clients in multiple settings; home, hospital, and long-term or residential care facilities. Palliative care programs in Nova Scotia deliver therapies designed to address the physical, psychological, social, spiritual and practical needs of both the individual living with a life-threatening disease as well as their family (Canadian Institute for Health Information, 2011). The majority of patients referred to palliative care programs in Nova Scotia are dying of cancer (NELS ICE, 2008), although rates of enrolment for persons dying of other diseases are increasing (Johnston & Lethbridge, 2014).

Since the initiation of this study (in 2010), Nova Scotia has developed an Integrated Palliative Care Strategy that aims to enhance palliative care services so that “all Nova Scotians can access integrated, culturally competent, quality palliative care in a setting of their choice” (Nova Scotia Department of Health and Wellness, 2014, p. 2). A progress report from 2014/2015 highlights the steps implemented since the strategy was released (Nova Scotia Department of Health and Wellness, 2015b). This includes increased accessibility to palliative care consultation teams, resource development, and establishment of a governance structure for accountability. The strategy seeks to engage members of the public and those who have experienced the palliative care systems and to identify a standardized palliative care training model for health care teams.

Palliative care at NSHA Central Zone

In Halifax, the NSHA Central Zone formerly began offering a palliative care program in 1988. In 2003, Capital Health (former name of NSHA Central Zone) and the District Continuing Care Program struck a partnership to form an Integrated Palliative Care Service (Capital Health and Cancer Care Nova Scotia, 2008). Capital Health Integrated Palliative Care Services (CHIPCS) offered services through the collaboration of existing health care providers. In this model, patients received care from a Primary Care Team (i.e., family doctor and Continuing Care home services) and/or a Palliative Care Consultation Team (i.e., Palliative Care physician and nurse). The Palliative Care Consultation Team offered services to patients in a variety of settings: hospital, clinic, home and long-term care. There is some evidence to suggest that CHIPCS resulted in a decline in emergency room visits among palliative care patients (a potential indicator of quality of care during the end-of-life) (Lawson, Burge, McIntyre Field & Maxwell, 2009)

In 2009, when the PATH program was first established, CHIPCS services were only available to individuals with an expected lifespan of less than 12 months and a diagnosis from one of the following diagnostic categories: Cancer, Cardiovascular Disease, Infectious Diseases (i.e. Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome or Hepatitis-C), Neurological Disorders, Renal Disease, and Respiratory Disease (Capital Health Integrated Palliative Care Service, 2010). CHIPCS Referral requirements were subsequently revised in line with SPICT™ Criteria (available at <http://www.spict.org.uk/>) with emphasis placed on having more open criteria for a baseline assessment (Dr. Rob Horton, palliative care physician; personal communication; Nov 19, 2013). Today, in NSAH Central Zone, Palliative Care providers are available to

support primary care provider and other members of the patients care team. Services include community and inpatient consultation, a 10-bed inpatient unit, and bereavement services (Nova Scotia Health Authority, 2017).

In the year PATH was introduced at NSHA Central Zone, approximately 1,100 new consultations were made to CHIPCS (Capital Health Division of Palliative Medicine, 2010), approximately half of which were in-patient consultations. Only 25% of individuals making use of this service had non-cancer illness as their primary diagnosis. Patients were generally between 60 and 90 years of age with an approximately equal gender split (52% male). Palliative services were generally incorporated into care when death was fairly imminent; after enrolment in CHIPCS 47% of participants had died within 39 days and 25% within 9 days. From the time they were admitted to the service, to the time of their death, patients spent the majority of their remaining days at home. Despite this fact, and the knowledge that individuals generally prefer to die at home (Tang, 2003), only about one quarter of patients achieved a home death (26%) (Capital Health Division of Palliative Medicine, 2010). The majority of patients died in hospital, fewer than half died on a Palliative Care Unit.

As a part of the Nova Scotia Integrated Palliative Care Strategy, work is currently underway to expand palliative care services by establishing hospice facilities (Nova Scotia Department of Health and Wellness, 2015b). Hospice, which is an appropriate setting for care for those who can no longer remain at home but do not need acute hospital care, is recognized to be an essential component of a comprehensive palliative

care system. The first provincially available 10-bed hospice care facility will be located in NSHA Central Zone (Halifax) and is anticipated to open in 2018. Plans are underway for two additional facilities to be established outside of Central Zone (Campbell, 2017).

The challenge: Caring for older adults nearing end-of-life

Despite the advances made since palliative care first emerged, dissatisfaction with end-of-life care is still apparent (Carstairs & Beaudoin, 2000; Heyland et al., 2005) and evidence indicates that the dying elderly often do not receive appropriate care as they approach death (Ahronheim, Morrison, Baskin Morris & Meier, 1996; Giles & Miyasaki, 2009; Morrison & Siu, 2000). The need for programs that better address end-of-life care for older adults in Nova Scotia has been acknowledged by the Nova Scotia Seniors' Secretariat (Nova Scotia Seniors' Secretariat, 2005) and the Nova Scotia Department of Health and Wellness (2015a).

The first steps to achieving appropriate end-of-life care and a 'quality death' are to understand current health conditions and identify a terminal illness early in the disease trajectory (National Consensus Project for Quality Palliative Care, 2009); however, these first steps are often not achieved (Cherlin et al., 2005). For most individuals, achieving an accurate understanding of current health and prognosis will be contingent upon a health care provider's ability to not only diagnose and prognosticate, but also to effectively communicate the findings of their assessment and impressions to the patient and their family. When it comes to providing this type of quality care to older adults with multiple co-morbidities and their families, physicians must overcome many challenges.

While the oldest old (i.e. those over 85) have a lower incidence of cancer (Evers et al., 2002) adults 65 years and older frequently have multiple, often interacting, medical conditions along with social vulnerabilities (Corpus Sanchez, 2007; Murray & Lopez, 1997; Rapoport et al., 2004). Accumulation of health deficits (e.g., disease, cognitive decline, lack of social support) results in a state of reduced resilience termed ‘frailty’ (Rockwood & Mitnitski, 2007). Frailty is an age-associated state that compromises one’s ability to withstand treatment and recover from injury or illness. Thus, complex medical treatments that are appropriate for healthier individuals may not be of benefit for older individuals who are vulnerable to the adverse effects of medications, treatments and procedures (Balducci, 2000; Fukuse, Satoda, Hijiya, & Fujinaga, 2005; Robinson et al., 2009; Travis et al., 2002).

For physicians, frailty creates a complex context for consideration of overall health, resilience to illness, and potential outcomes to treatment (Rockwood & Mitnitski, 2007). Lack of recognition of frailty, and its associated prognosis, can result in an overestimation of life expectancy and inadequately informed decision-making (Mitchell, Kiely, & Hamel, 2004; Murphy et al., 1994). As a consequence, older adults may be offered (and choose to receive) treatments that have little chance of benefiting their overall health status, physical symptoms may be poorly controlled, and significant psychological distress may be experienced (Evers et al., 2002; Ferrell & Bruce, 1995; Hanson et al., 2008; Teno, Weitzen, Wetle, & Vincent, 2001; Travis et al., 2002)

Even when frailty is brought to the forefront of care, physicians have few resources to draw upon for prognostication and care planning in the context of multiple comorbidities. Physicians must rely on evidence-based care guidelines to determine the most appropriate course of medical treatment. However, such guidelines are developed based on studies that consistently exclude frail, older adults, and are therefore of limited utility to physicians in the context of frailty (Travis et al., 2002; Van Spall, Toren, Kiss, & Fowler, 2007; Mallery et al, 2015). Given the lack of evidence-based tools to guide care when a complicated health profile is presented, it is not surprising that health care providers can have difficulty recognizing and discussing prognosis with frail older adults and their families (Hanson et al., 2008; Travis et al., 2002).

Effective communication is of utmost importance during the care of seriously ill patients (Heyland et al., 2006); however, communication strategies for health care providers to use when caring for frail older adults have yet to be developed or studied. Traditional recommendations advocate that health care professionals spend more time listening to patients and their families rather than talking (Back, Arnold, Baile, Tulskey, & Fryer-Edwards, 2005; McDonagh et al., 2004). While this approach appears patient-centered, it assumes that pertinent information regarding health status and prognosis has been previously communicated and understood; in practice, this is rarely the case (Black et al., 2009). Thus, frail individuals and their families often end up ill informed about prognosis (Hancock et al., 2007) and unaware of limited life expectancy (Zapka et al., 2006) and may state treatment preferences that are not in alignment with prognosis.

In addition to the difficulties associated with understanding the health profile of frail older adults, and communicating these findings to patients and their families, the terminal trajectory of individual illnesses (e.g. dementia) may also be overlooked or underemphasized. Without this recognition, the opportunity for appropriate care planning is missed. A link exists between frailty and cognitive impairment; cognitive impairment is considered a ‘deficit’ contributing to a state of reduced resilience in Rockwood and Mitnitski’s model of frailty (2007). While the mechanisms behind this link are not well understood, a number of epidemiological studies have reported that cognitive impairment increases the risk of frailty, and that frailty increases the risk of future cognitive decline (Robertson, Savva, & Kenny, 2013). Dementia is a progressive form of cognitive impairment that is often not recognized (or described) as ‘terminal’ until the latest stages of the disease are reached (Forbes, Bern-Klug, & Gessert, 2000; Mitchell et al., 2004; Sachs, Shega, & Cox-Hayley, 2004). A diagnosis of dementia has specific implications for end-of-life care due to the progressive changes in cognition experienced as the disease progresses. Individuals with dementia require more time to discuss and make health care decisions with their health care provider and family, and will eventually require a care partner to act as a surrogate decision maker (due to loss of capacity) (Evers et al., 2002). Without the early recognition of dementia as a terminal illness, and the establishment of advanced care goals, patients and their care partners are often not prepared for the health care decisions associated with end-stage dementia, which can lead to inappropriate treatment decisions (Forbes et al., 2000; Hirschman, Kapo, & Karlawish, 2006). Unfortunately, even in situations where early and accurate prognostication about a terminal trajectory does occur, this does not ensure appropriate planning for impending

death as both the patient and/or the care partners may not agree or accept the physician's description of prognosis (Carrese, Mullaney, Faden, & Finucane, 2002; Cherlin et al., 2005).

Health care decision-making

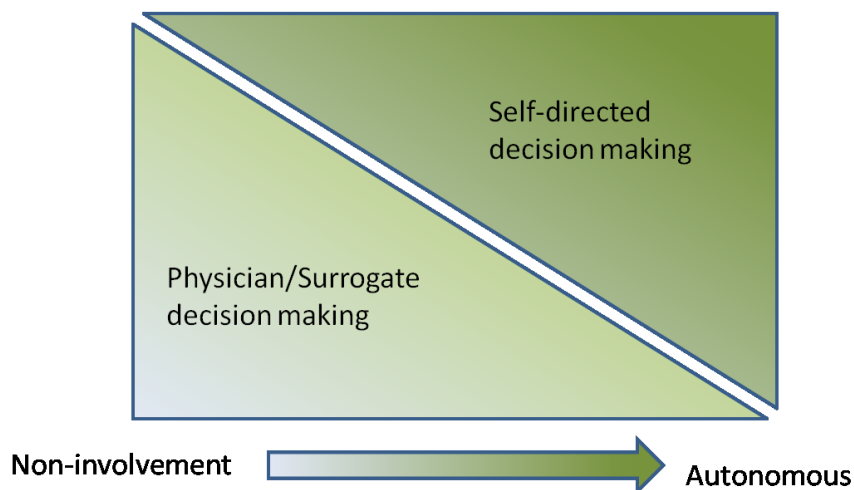
When making medical decisions, high-quality and sensitive discussions about prognosis, and better consideration of health status can improve care and ensure appropriate treatments or therapies are administered (Vollandes et al., 2009). However, most individuals are often reluctant to have such conversations about end-of-life care, and may resist discussions about likely future health care scenarios (Carrese et al., 2002). Care partners may also avoid initiating such discussions for fear of upsetting the patient or as a result of their own lack of acceptance of the diagnosis and prognosis (Boyd et al., 2010; Cherlin et al., 2005; Forbes et al., 2000).

Desired involvement in the decision-making process

Physicians must tailor their approach to discussing health status and care planning based on individual preferences for decision-making involvement. Thompson (2006) describes differences in patient-desired involvement ranging from non-involvement to independent decision-making. *Non-involvement* in treatment decision-making can stem from a variety of factors including lack of cognitive abilities, the desire to have a surrogate as the decision-making agent, or faith in the professional's ability to do what is best. The next level of decision-making, *information-seeking/information receptive*, describes a patient who desires or is willing to be given relevant information regarding their prognosis.

Information may provide a means for some patients to maintain a sense of control over their lives, and is seen as an essential pre-requisite for decision-making. The next level, *information-giving/dialogue* is reached by those with confidence in their knowledge and a desire to be heard by their health care providers. *Shared decision-making* occurs when patients and their health care providers reach a state of collaboration where the patient (or their surrogate decision maker) is afforded the opportunity to make an informed choice with the health care professional's guidance. Finally, *autonomous decision-making* is enacted by those who believe themselves to have an equal or superior ability to make decisions compared to their health care provider.

Figure 1. Involvement in health care decision-making.



Many frail older adults may have limited ability to contribute to health care decision-making at end-of-life due to cognitive impairment. Smebye, Kirkevold and Engedal (2012) expanded upon Thompson's (2006) model for participation in decision-making by

applying the 4-level framework to health and daily care decisions made by and for persons with dementia. Smebye et al. (2012) found considerable variability in how persons with dementia are involved in their own decisions, and expanded Thompson's (2006) mode to include two additional levels of involvement. *Pseudo-autonomous decision-making* described situations where it appeared that choices had been patient-directed, but in actual fact, the essential pre-requisite for decision-making, information, had not been conveyed to the patient. This occurred when individuals with dementia were not adequately informed about their options, or when the family or care provider assumed they knew the patient's values/preferences. While decisions made pseudo-autonomously may not always be made based on false premises, such decision-making provides the opportunity for decisions to be made that are not in line with the patient's wishes. *Delegated decision-making* occurred when responsibility for decision-making was actively entrusted to another, potentially initiated by the recognition of one's own current or future cognitive limitations.

Substitute decision-making

With the aging population and increasing rates of incapacitating illnesses such as dementia (Alzheimer Society of Canada, 2010), a growing number of care partners will be delegated with decision-making responsibilities. It is projected that by 2036 there will be 9.8 million seniors living in Canada (Statistics Canada, 2006), an estimated one quarter of whom will require a substitute decision maker before death (Silveira, Kim & Langa, 2010). Thus, it is reasonable to expect that at least 2.5 million care partners will take on delegate decision-making responsibilities in the coming decades.

Understanding patient preferences

In some instances, the loss of capacity can occur suddenly, in others it is a gradual, predictable loss; such is the case for persons with dementia. Early diagnosis of a progressive illness can provide an individual the time to prepare for end-of-life, including the opportunity to select a surrogate decision maker, and to share with this person their specific wishes and directives. This process is important because as end-of-life care decisions arise the surrogate will likely be called upon to execute 'substituted judgment' and determine what the patient would choose if they could (Emanuel & Emanuel, 1992). However, the opportunity for pre-emptive planning and communication is often missed due to a lack of understanding and acceptance of a terminal prognosis (Cherlin et al., 2005) or the postponement of discussions until they are no longer possible (i.e., the individual no longer has the capacity to fully participate in the decisional process) (Lingler et al., 2008). Additionally, many individuals are reluctant to think about end-of-life, let alone discuss hypothetical scenarios and treatment preferences with their family (Black et al., 2009; Carrese et al., 2002; Hirschman et al., 2006).

When conversations surrounding end-of-life care do occur, patients are often reluctant to relay instructions regarding treatment decisions that could be expected to arise, and instead prefer to discuss only non-specific desires such as not wanting to be kept alive by machines or "extraordinary measures" (Black et al., 2009, p. 643). Such vague statements are too broad to provide constructive guidance or support for the surrogate when they are called upon to make delegated decisions during health crises. Conversely, statements may be too specific, placing emphasis on medical interventions rather than outcomes (Rosenfeld, Wenger & Kagawa-Singer, 2000), resulting in requests that are not feasible

to execute (Perkins, 2007). Equipped only with instructions that ignore the present context, care partners may find it challenging to provide substituted judgment, which is regarded as the preferred method for substitute decision-making as it aims to maximize the patient's autonomy (Emanuel & Emanuel, 1992).

Without the benefit of previous discussions concerning care outcomes, surrogates are often at a loss to infer what decisions the patient would have made (Hirschman et al., 2006). Surrogate decision makers have described surmising what the patient's wishes would be based on past experiences with the individual (Hirschman et al., 2006); informal conversations, values previously expressed, and from decisions made in other health-related contexts (Black et al., 2009). Surrogates may also gather information about the patient's wishes from the individual's friends and/or other family members. In situations where substitute judgment cannot be used (because the delegate has no insight or awareness of what the patient would have wanted; Hirschman et al., 2006), surrogates are left to make their own decision based on their personal assessment of what is in the patient's best interests (Emanuel & Emanuel, 1992).

Given that many individuals are reluctant to think about and discuss end-of-life in great detail (Black et al., 2009; Carrese et al., 2002), it is perhaps not surprising that delegated decision makers routinely have difficulty answering questions regarding the patient's values and care goals (Morrison & Meier, 2004) or that decisions made by surrogates are often not in agreement with patient preferences (Fried, Bradley, & Towle, 2003; Moorman & Carr, 2008; Zikmund-Fisher, Sarr, Fagerlin, & Ubel, 2006).

Advance directives

One method of advanced care planning is the recording of future care wishes through a legally recognized document – an Advanced Directive. The utility of Advanced Directives has been debated in the literature (Wilkinson, Wenger & Shugarman, 2007). Some studies have found an association between the use of such documents and decisions being made in accordance with patient preferences (Silveira et al., 2010), while others have shown that these directives do not improve a surrogate’s ability to predict patient preference (Hare, Pratt & Nelson, 1992; Moorman & Carr, 2008) or make decisions that accurately reflect the patient’s wishes, (Chambers-Evans & Carnevale, 2005)

Many people do not believe that it is necessary to formally record their health care preferences and would prefer to verbally convey their wishes to a designated decision maker (Hawkins, Ditto, Danks, & Smucker, 2005), despite the fact that often these same individuals will have completed formal wills and funeral plans (Carrese et al., 2002). Individuals have reported not being ready to have these types of discussions, their opinion being that advanced plans cannot be done successfully, fear that the conversation will be upsetting, feelings of uncertainty, and a desire to ‘live in the present’ as reasons contributing to their avoidance of care planning (Carrese et al., 2002).

When Advanced Directives are completed, they frequently document little more than a proxy decision maker (Teno et al., 1997) and/or vague descriptions for future care (e.g., “no extraordinary measures”, “no artificial heroics” (Black et al., 2009, p. 644). When more specific instructions are recorded they can fail to allow for the context of future health in a way that improves the surrogate’s ability to honour the patient’s wishes (Ditto

et al., 2001; Moorman & Carr, 2008) and may only be relevant to situations where death is near and certain (Carrese et al., 2002)

Even in ideal situations, when the surrogate has reviewed a carefully crafted future care plan, and had the opportunity to discuss it with the individual, patient preferences may not be actualized (Ditto et al., 2001) for several reasons: the need to reach family consensus, the patient's quality of life, as a result of medical advice, or because the directive would result in a decision being made that would not be in the patient's best interest given their current cognitive status (Hirschman et al., 2006). Additionally, surrogates tend to over-predict patient preferences for life sustaining treatments (Moorman & Carr, 2008; Zikmund-Fisher et al., 2006). In a study by Ditto (2001), surrogates' choices were correct only 70% of the time for hypothetical situations where the patient had Alzheimer's Disease, with the most accuracy demonstrated in scenarios where the patient's current health status was used, and in extreme examples known specifically to be against the patient's wishes (e.g. coma with no chance of recovery).

Discrepancy between treatment decisions may be attributed to differing values towards end-of-life (Hare et al., 1992). When considering future treatment decisions, patients place high importance on the level of burden placed on their families and time left to live, while care partners consider these issues to be less significant than the patient's level of pain or suffering. Over-treatment decision may also be the result of a care partners fear of not doing enough and the desire to feel everything possible was attempted (Chambers-Evans & Carnevale, 2005; Moorman & Carr, 2008). For example, in a study of how

decisions were made to withhold cardiopulmonary resuscitation (Hayes, 2012, p. 79), one relative of a 100-year-old-patient was reported as saying “*If there’s a chance she might survive with that treatment, then I don’t want to be the one to say no to it.*”

Despite the lack of conclusive evidence to support advanced directives as a useful tool for ensuring patient wishes are fulfilled, the completion of such documents is generally encouraged. At the same time, lack of advanced planning on the part of the patient places the burden of decision-making on a surrogate, usually a spouse (Hare et al., 1992). More than one quarter of older adults may require a care partner to act as a decision maker before their death (Silveira et al., 2010); however, discussions around the completion of Advanced Directives often do not happen before an individual loses decision-making capacity (Hirschman et al., 2006; Lingler et al., 2008).

The experience of the surrogate decision maker

The role of the surrogate decision maker is not an easy one; end-of-life decision-making occurs in a context of impending loss and anticipatory grief (Meeker & Jezewski, 2009; Wendler & Rid, 2011). Care partners of terminally ill patients experience the burdens associated with provision of care at end-of-life, and from witnessing the patient in physical distress (Prigerson et al., 2003). With the addition of decision-making responsibilities, the health risks associated with performing caregiving duties are significantly increased (Christakis & Iwashyna, 2003; Rabow, Hauser, & Adams, 2004). This burden can persist for months, and sometimes years (Wendler & Rid, 2011).

A systematic review of the effect of the role of surrogate decision maker has revealed that at least one third of surrogates experience stress, anxiety and other emotional burdens as a result of making or helping to make treatment decisions for an incapacitated person (Wendler & Rid, 2011). Surrogates often describe their role as being difficult, intense, painful, overwhelming, devastating and/or traumatic. Surrogates may experience pain from loss of a relationship, guilt over difficult decisions and feel that they have abandoned their loved-one when, for example, the decision to place someone in long term care is made (Forbes et al., 2000). Even when surrogates describe themselves as 'satisfied' with the overall decision-making process, emotional burdens are still reported (Wendler & Rid, 2011).

One of the most difficult decisions a surrogate may face is the choice to withdraw potentially life-sustaining treatment. This situation requires care partners to balance their decision-making responsibility with their own emotions as they contemplate the implications of their choice. An interpretative phenomenological study of family decision-making in the Intensive Care Unit describes the process of end-of-life decision-making as experienced by substitute decision makers (Chambers-Evans & Carnevale, 2005). The first steps involved understanding the patient's prognosis as being terminal, and accepting that it would be impossible for the patient to survive as the person the surrogate remembers them to be. In order for these first steps to take place, decision makers needed to have access to, and process, the information provided by professionals, and then translate the knowledge into something they could share with other family members and friends. Next, surrogates needed to shift their thinking from fighting the

illness to letting go of the person. Surrogates were torn between the desire to preserve the patient's life at all cost, and the knowledge that they would not consider the future predicted as an acceptable quality of life. During this process, surrogates experienced "pre-grief" (p. 41) as they accepted the inevitability of the patient exiting their life. Finally, surrogates struggled to find peace with the decision to withdraw treatment. Often this peace was achieved through conversations with others where they sought affirmation that the decision to withdrawal life-sustaining treatment was the correct option.

The process of end-of-life decision-making involves significant guilt, doubt and grief (Meeker & Jezewski, 2009; Wendler & Rid, 2011). Surrogates may experience a longing for the patient to die on their own so that they will not need to make the final decision with regards to withdrawal of life support (Wendler & Rid, 2011). When this is not the case, surrogates can be left with long-lasting questions of whether they made the right decisions (Chambers-Evans & Carnevale, 2005; Tilden, Tolle, Nelson, Thompson, & Eggman, 1999). In order to move forward, surrogates need to believe that they have carried out the individuals wishes, and they must have the sense that decisions were made to ensure everything possible was done in the patient's best interest (Wendler & Rid, 2011).

A meta-synthesis examining the caregiver's experience of the decision to withdrawal life-sustaining treatment reveals that surrogates respond to their role in a dichotomous manner – they experience significant trauma and burden, yet also deep fulfillment and empowerment by their role in protecting the patient's best interests (Meeker & Jezewski,

2009). Surrogates experience less guilt and stress when they are confident in their understanding of what the patient would have wanted (Wendler & Rid, 2011); however, it is interesting to note that confidence has not been shown to ensure accurate determination of patient wishes (Hare et al., 1992).

It is evident that the role of substitute decision maker is a complicated one to take on. The experience is heavily laden with burden, negative emotions, stress and anxiety. It is therefore not surprising that surrogates often need to rely on other family members for support, believing that the responsibility of decision-making is too great to be born by one person (Meeker & Jezewski, 2009). Health care professionals can improve the surrogates experience by ensuring communications are of a high quality (Wendler & Rid, 2011), by developing honest and sincere relationships with the surrogate (Torke, Alexander, Lantos, & Siegler, 2007) and by ensuring that surrogates themselves feel cared for during the process (Wendler & Rid, 2011).

CHAPTER III. The Palliative and Therapeutic Harmonization (PATH) Program

Nova Scotia has recognized the need for programs that support the end-of-life care needs of frail older adults (Nova Scotia Seniors' Secretariat, 2005; Nova Scotia Department of Health and Wellness, 2015a). In response, two geriatricians at NSHA developed the PATH program as a service for frail older adults and their families (or other care partners). PATH offers clients a comprehensive geriatric assessment followed by in-depth discussion about prognosis and medical decision-making within the context of frailty and (where applicable) dementia.

PATH was first offered at the Geriatric Ambulatory Care Clinic (GACC) at the QEII Hospital (NSHA Central Zone) in September of 2009 by a team of nurses and nurse practitioners, one social worker, researchers, and two physician team leads. Using the model established by the GACC team, PATH has been modified for delivery in in-patient, community, and long-term care settings while maintaining four key principles that guide program development (see Table 1, adapted from Mallery & Moorhouse, 2011).

Table 1. The Principles of PATH

Principle	Rationale
Knowledge is power	People want and deserve accurate information about their health status and how their health conditions will affect them in the future
Frailty must be at the forefront of decision making	Physicians and other health professionals must consider how all of a patient’s illnesses and potential treatments interact
Honest communication is essential	Patients and families can only make health care decisions that are right for them if they grasp the true nature of how a situation will unfold. While bad news is hard for doctors to give, and many do not want to take away hope, they must provide honest and timely information about what the future holds
It all comes down to asking the right questions	By taking an organized approach, patients and their families learn how to make more carefully considered medical decisions by carefully exploring the risks and benefits of treatments and procedures

Data from the first 150 consecutive individuals to complete PATH at the GACC and as a part of the inpatient consultation service at the QEII Hospital have been reported (Moorhouse & Mallery, 2012). The mean age of these patients was 81 years old (SD +/- 7.2). The patients generally had multiple co-morbidities and were, on average, severely

frail (according to the Clinical Frailty Scale; Rockwood et al., 2005). The majority of patients had a pre-existing (60.7%) diagnosis of dementia, while a further 8.0% received a new diagnosis of dementia during the PATH process. Most patients (76.7%) were unable to participate fully in care planning discussions because of dementia or delirium.

The PATH Process

PATH uses a standardized approach to systematically review the health status of older adults with multiple severe illnesses to ensure patients and their care partners gain a more complete understanding of current health status (Mallery & Moorhouse, 2011). The PATH program is available to both inpatient and outpatient populations of frail older adults with chronic health issues (often including dementia) when families or care partners have questions about prognosis and future care planning, and where the benefit of aggressive medical or surgical interventions may be questioned (Moorhouse & Mallery, 2012).

PATH uses a three-step process commonly characterized by the following tasks:

- (1) Understand – a comprehensive assessment of health status, including identification of health trajectory;
- (2) Communicate - an in-depth discussion about health status and expected prognosis; and
- (3) Empowerment – a portable, flexible care plan is implemented.

Inpatient consultations receive a modified version of the PATH program and materials; therefore, this study will only examine the outpatient population seen at the GACC who have completed each of the three PATH tasks.

The PATH model differs from more traditional therapeutic models of care in a number of ways. First, PATH values the importance of acknowledging frailty in relation to current health status and expected prognosis, and recognizes that dementia and incapacity profoundly influence decision-making, requiring additional time and communication with patients, their families and/or other care partners (Evers et al., 2002). By ensuring that frailty and dementia are assessed, and that their implications are considered during medical decision-making and care planning, PATH aims to ensure that older patients do not receive interventions that will either be of little benefit or result in outcomes that are considered unacceptable or undesirable (e.g. declines in cognition or function).

Second, unlike other palliative-specific programs, which are often disease-specific and focus on comfort care, PATH aims to serve as an early intervention program for frail older adults. In this way, PATH can help patients and their care partners recognize frailty and terminal trajectories at an early stage, identify remediable disease, assist in the understanding of diagnoses and prognoses, encourage dialogue about care goals, enable patients and their families to avoid treatments and procedures that may compromise quality of life, and plan for health care decisions well before palliative services are required.

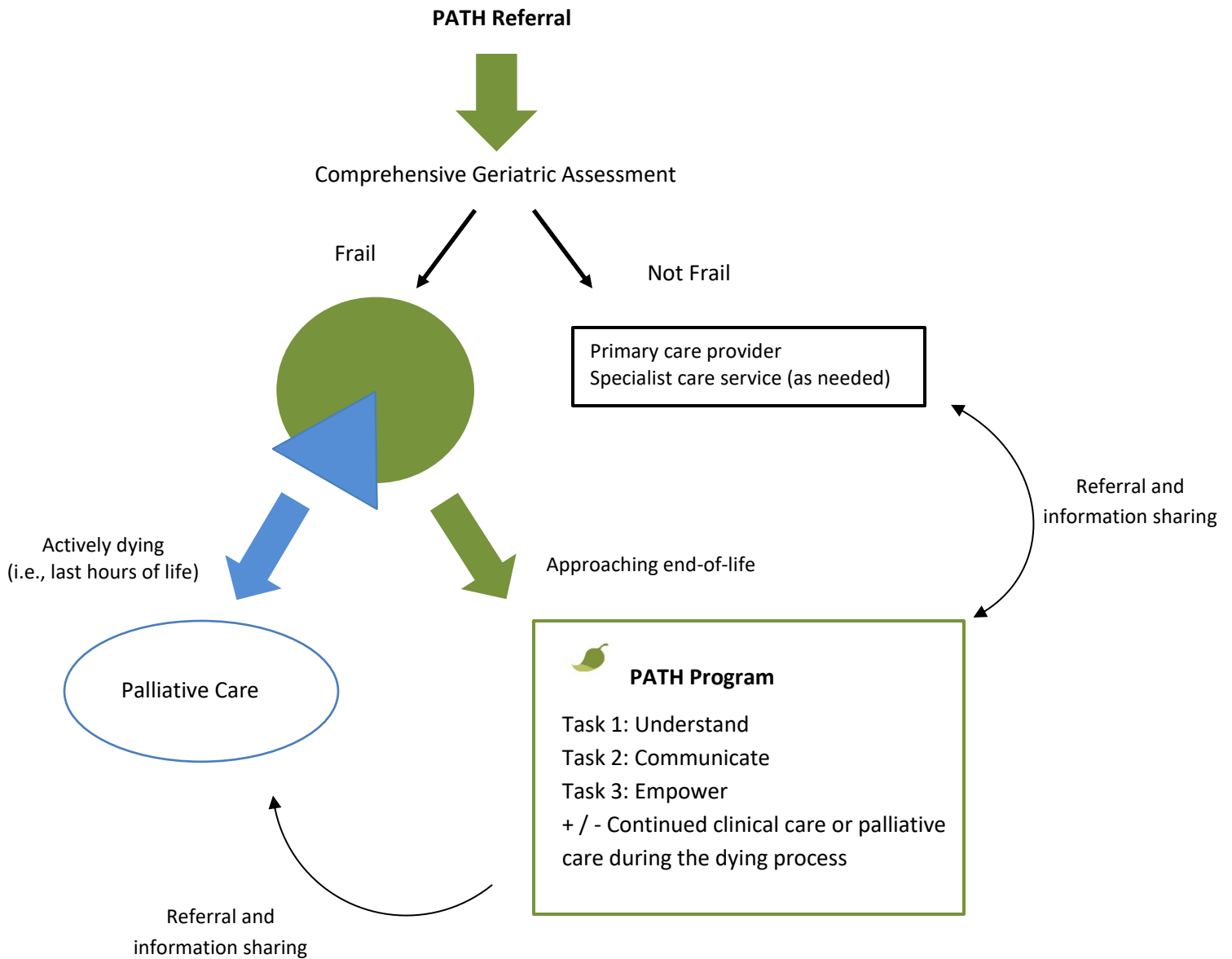
Third, PATH addresses the limitations of traditional decision-making through a process that requires patient and care partner involvement, whereby a shared understanding of health status is reached and a procedure for making medical decisions within the context of frailty is taught (Mallery & Moorhouse, 2011; Moorhouse & Mallery, 2012). The PATH process ensures all individuals involved in care and decision-making are well informed about current diagnoses and prognosis. Families and other care partners are encouraged to discuss care planning and decision-making before health crises are experienced or additional care requirements become necessary.

Finally, PATH aims to ensure that patients and their care partners (potential substitute decision makers) are empowered to make future health care decisions in the context of frailty, and other chronic progressive conditions. By identifying individualized goals of care, sharing these goals with family members and other care partners, and equipping those who will be responsible for health care decisions when changes in health status are experienced with a portable care plan, participants leave PATH with the tools required to make informed health care decisions in the future.

Referrals to the PATH program at NSHA are accepted from primary care physicians and consulting specialists when questions arise as to the benefit of potential treatments and procedures (Mallery & Moorhouse, 2011). PATH may be the first exposure a patient and their family has to palliative options, and can assist families with the recognition of a terminal prognosis.

Referred patients and their care partners complete the first task of PATH, *Understand*, which involves a Comprehensive Geriatric Assessment (CGA) and allows the team to assemble a complete picture of the individual's health. Patients are assigned a frailty score based on the Clinical Frailty Scale (Rockwood et al., 2005). Depending on the result of assessment (see Figure 2.), a patient is deemed appropriate (or not appropriate) for the full PATH program. Due to resource restrictions, PATH generally aims to see patients with moderate to severe frailty (i.e., clinical frailty score ≥ 6). If the assessment identifies a patient as being in the last hours of life they will be referred directly to palliative care services (i.e., CHIPCS). For patients who are not categorized as PATH appropriate, the referring physician and/or the primary care physician is informed of the assessment outcomes and physician recommendations.

Figure 2. Referral to PATH and patient categorization



Patients who are identified as PATH-appropriate will go on to complete the next two tasks of PATH. The second task is to *communicate* the CGA findings through a semi-structured presentation of current medical conditions affecting day-to-day function and quality of life. Once a clear understanding of current health status is established, the discussion moves to prognosis, potential health issues that may arise, and the patients' and care partners' values and goals of care.

Finally, the last task of PATH is to *empower* patients and the families to make informed health care decisions. Care partners are taught the types of questions to ask when health crises arise in order to ensure that future decisions are properly informed and in-line with agreed upon goals of care. The aim is to achieve a blend of palliative care and therapeutic treatments personalized to each individual, and for decision makers to acquire the knowledge and strategies needed to make future health care decisions that protect the patient's best interests and quality of life.

When PATH is complete, the referring physician and/or primary care physician is informed of the outcomes of the assessment, any medical decisions that have been made, and future goals of care decided upon. A continued connection with the PATH team is often maintained; patients may continue to receive clinical care as health status changes and care partners may request additional visits to address their questions and concerns that arise during acute changes in health status ("the health crisis"). The PATH service does not replace the need for other palliative care services at end-of-life. However, in some cases, where it serves to eliminate transitions of care during a health crisis at the

end-of-life, the PATH team may be directly involved in the provision of palliative care during the dying process.

Patient and family experiences

At the end of the PATH process, the first 60 participants were invited to complete an anonymous, self-administered exit survey (not tested for reliability or validity) designed to measure the extent to which they understood their own, or their family member's, medical health as well as their overall confidence in speaking with health professionals about health concerns. The informal survey contained 14 questions with responses on a scale of one to seven (e.g., "not at all" to "completely"). Five questions asked about their past (i.e., prior to PATH) knowledge and comfort with the health situation and decision-making and five questions asked about their current knowledge and comfort with the health situation and decision-making. Four questions asked about their experience at PATH (e.g. was it emotionally upsetting). The final two open-ended questions asked respondents to describe what was "good about this clinic" and what could be done "to improve the PATH process".

Exit surveys were returned by 36 of the first 60 participant dyads, a 60% response rate. While the literature does not provide a definitive minimally accepted response rate for survey research, the general consensus is that at least half of potential respondents should have completed the instrument (Draugalis, Coons, & Plaza, PharmD, 2008). Analysis of completed surveys showed that before coming to the PATH clinic, fewer than 35% of respondents felt they had a very strong or complete or understanding of how medical

conditions interacted, what to expect in the future, how conditions would affect future health care decisions, and what information they needed to make good medical decisions. Only 53% felt completely confident about talking to medical professionals about their health. After PATH, the proportion of respondents who believed they had a strong or complete understanding of these issues increased significantly. For example, after PATH, 91% of decision makers felt they knew what information was needed to make medical decisions (vs. 34% before PATH). Satisfaction with the process was unanimous, although 65% of the respondents found the process upsetting. Given the knowledge that respondents of satisfaction surveys tend to over-report positive experiences (Ingram & Chung, 1997), limited insights can be gleaned from this data.

In 2015, a six-month follow-up phone call was implemented as a revised standard of care and quality assurance. An examination of 32 randomly selected interviews has reported on participant satisfaction and discusses themes of care partner empowerment, information, and choice (Moffatt, Mallery & Moorhouse, 2016).

Rationale of the proposed research

At the time this study was initiated (2010) the only data providing insight into the participants experience at the PATH had been collected through an informal exit survey completed by 36 of the first 60 participants. This survey was not tested for reliability or validity and failed to capture many subjective aspects of the impact PATH has on participants.

The purpose of this study was to describe in greater detail the experience of PATH participants. Care partners are often called upon to act as substitute decision makers during a health care crisis, and he/she may complete tasks two (*Communicate*) and three (*Empower*) without the patient (depending on cognitive status), therefore the specific experience of the care partner is examined. The preceding review of the literature provided background context for the current availability and use of end-of-life care in Nova Scotia, and summarized the literature on medical decision-making, and the surrogate's experience of making decisions for another at end-of-life.

This study provides insight into the role PATH plays in the care partners experience of caring for and making decisions for/with a PATH patient, and a description of the program's strengths and weaknesses from the perspective of the care partner. The results of this study can be used to inform future directions for program development. Insights can be used to modify program elements to ensure participants have the opportunity to acquire the skills necessary for handling the stressors and decisions associated with end-of-life, and to ensure the most beneficial aspects of PATH are included in future training materials for additional health care settings. Results may also be used to modify the existing exit survey, so that it may be used in the outcome evaluation of implementation of the PATH model elsewhere.

CHAPTER IV. METHODOLOGY

The purpose of this study was to provide greater insight into the experience and outcomes of PATH participants. Qualitative description was employed to gain an understanding of the role PATH plays in the experience of a care partner and substitute decision maker, and to explore the meaning of the experience. This chapter presents the study design, research methods and measures taken to protect human subjects, data collection, and the analysis process.

Qualitative description

To better inform clinical practice, the developers of the PATH program expressed interest in improving upon the initial outcome-evaluation questionnaire presented to the first cohort of PATH participants, and a desire to better understand the direct impact of PATH on both care partner and patient participants. A generic qualitative methodology was identified as appropriate for meeting the study objectives (Caelli, Ray, & Mill, 2003).

The qualitative description approach, a form of naturalistic inquiry described by Sandelowski (2000, 2010), was selected as a model based on its usefulness in tailoring clinical investigations, scales, needs assessments and questionnaires in mixed method and small independent research studies (Sullivan-Bolyai et al., 2005). The goal of qualitative description is to understand an experience from the participants' perspective, and to explore the meaning of the experience.

The qualitative description approach captures descriptions of subjective experiences in the participants' own language, and is useful for answering questions of special relevance

to practitioners (Sandelowski, 2000) and thus served the overarching objective to better understand the experience of the care partner in the PATH program. In this study, qualitative description was used to gain rich, minimally transformed descriptions of the participants' experience with PATH in order to appreciate the role the program played in their experience as a care partner and surrogate decision maker for a frail older adult nearing end-of-life.

Qualitative description studies have been criticized for lacking rigour and credibility (Milne & Oberle, 2005). In this study, several strategies were employed to ensure that authentic and credible data were collected. Participant-driven data was sought through the use of a semi-structured, flexible topic guide designed to allow participants to share their subjective experience and to decide for themselves what they felt was important to share. Interview transcripts were re-read at least twice while listening to the interview recordings to ensure accuracy. Throughout the study it was important to identify and reflect on researcher bias. The inclusion of a methods advisor, Dr. Emily Marshall, who was not involved in the development and delivery of the PATH program helped contribute to the integrity of the study. Dr. Marshall was consulted as methodological decisions were made, during the analysis phase when establishing of a framework for coding, and reviewed the findings to ensure that both positive and negative care partner reports were represented.

Setting

This study took place at the QEII Health Sciences Centre of the NSHA in Halifax, the initial PATH program site. PATH is available as inpatient consultations and as an outpatient service with care delivery available in Geriatric Ambulatory Care Clinic, at home, or at a patient's long-term care residence.

Gaining Entrée

This study was made possible due to my long-standing relationship with Dr. Paige Moorhouse, a co-developer of the PATH program. I first became involved with PATH during my Master's degree program at Dalhousie University, while working with Geriatric Medicine Research at the QEII Health Sciences Centre. My experience contributing to the creation of standardized client packages and assisting with the collection and analysis of satisfaction surveys led me to consider conducting my thesis research with PATH participants. Both PATH physicians, Dr. Paige Moorhouse and Dr. Laurie Mallery, were receptive to my proposed study and helped me to gain funding from the Capital District Health Authority Research Fund.

Researcher Stance

As a Research Assistant employed with Geriatric Medicine Research from 2005-2014, I have worked on a variety of projects involving individuals with dementia and their caregivers. These projects included qualitatively coding video-recorded interviews with patients with dementia and their care partners, as well as interviewing patients with dementia and their family members for clinical drug trials.

From my experience working with Geriatric Medicine and the PATH program, I have gained insight into how health care is accessed and utilized by seniors. As a result, I have adopted an appreciation for the challenges associated with providing care to an elderly population, the demands placed on family care partners, and the difficulties associated with achieving optimal quality-of-life for frail individuals. As a result, my personal opinion regarding the responsibility of individuals with dementia and their families/care partners is that they have to be active participants in their health care. Through my work, my thoughts on appropriateness of care in the context of terminal illness have evolved.

The research questions for this thesis have stemmed from my experience working with Dr. Moorhouse, and assisting with the development of PATH program materials. Dr. Moorhouse is a supervisor for this project and acted as a content expert and advisor.

Dr. Emily Marshall acted as a methods advisor for this project. Dr. Marshall is a mixed-methods researcher in the Department of Family Medicine at Dalhousie University, who has assisted the Geriatrics team with qualitative projects in the past. Dr. Marshall's research focuses on community-based primary health care services. For example, as an Investigator with the Network for End of Life Studies (NELS), Dr. Marshall studied a new approach to delivering primary care in long-term care facilities. Dr. Marshall is involved in studying the clinical care of frail older adults and therefore likely brings with her a certain degree of bias; however, she was not involved in the development or delivery of PATH. Her involvement helped to mitigate the biases of Dr. Moorhouse and myself.

This research study was initiated in June of 2010 with the final analysis completed in November of 2017. During this time, additional studies of the PATH program have been published (Moorhouse & Mallery, 2012; Moffatt, Moorhouse & Mallery, 2016). The results of these studies did not inform the initial coding and analysis of the study data, however I knew the results when the bulk of the findings and discussion were formulated.

Participant Selection

The PATH process involves three major tasks: comprehensive geriatric assessment (*Understand*), in-depth discussion of health status and prognosis (*Communicate*), and creation of a portable, flexible care plan (*Empower*). All care partners who completed the three PATH tasks during the study recruitment phase (July 2010 – May 2011) were eligible for this study. The purpose of the study was to gain a better understanding of the care partners experience of completing the PATH process, and how receiving care from the PATH service had impacted their experience caring for a frail, older adult nearing end-of-life. As such, care partners who did not complete all three PATH tasks (either due to personal choice or because the patient was not deemed PATH-appropriate; Figure 2.) were not approached for participation. No other inclusion or exclusion criteria were imposed.

Maximum variation sampling (Sandelowski, 1995) was employed to explore care partner experience across a range of varied cases. Participants were initially recruited on a chronological basis; however, recruitment procedures were modified to sample for care

partners of individuals with a variety of primary diagnoses (e.g., dementia, renal failure, Parkinson's disease, heart failure, cancer). Additionally, in order to achieve maximum variation, participants were purposefully selected to achieve variation in post-PATH perspectives. For example, some participants had an opportunity to execute the decisions made during PATH, utilize the PATH decision-making resources, and were given an extended time to reflect upon their experience. Other participants, who had only recently completed PATH, had little time to apply the lessons of PATH, but would potentially be better able to provide more detail with regards to their recent experience with completing the PATH tasks.

A total of 13 care partners participated in 11 interviews; in two of instances care partners preferred to participate in dyads as they felt they completely shared the PATH experience with another family member. All but one participant attended PATH with an individual diagnosed with a dementia (though this was not always the primary diagnosis or the diagnosis prompting referral to the program). Seven care partners attended PATH with a parent, four with their spouses, one with a sibling and one with another extended family member

Human Subjects Consideration

The study protocol was approved by the Research Ethics Board of the former Capital District Health Authority (Category B, CDHA-RS/2011-060) on June 15, 2010. As stated in the *Research Ethics Review Cooperation Agreement*, created between Dalhousie University, the IWK Health Centre and the Capital District Health Authority (2006),

projects that are reviewed by either the CDHA or the IWK do not require additional review by the Dalhousie University Research Ethics Board. The study currently falls under the jurisdiction of the Nova Scotia Health Authority (NSHA-RS/2011-060)

Recruitment and Informed Consent

A recruitment letter was included in the standardized PATH client packages, which provided a general overview of the study and emphasized the voluntary nature of participation (Appendix A). Individuals were requested to indicate on the form letter if they were interested in being contacted (or not) and return the letter to a member of the PATH team. The team, including the nurses and physicians, assisted with recruitment by notifying me when a care partner had expressed interest in participating, and then provided me with the individuals contact information and a brief verbal summary covering the context of their participation and potential to provide rich narrative during an interview (e.g., displayed a willingness to interact with the PATH team, actively participated in the decision-making and care planning process, able to share and articulate their experience)

Once I received a potential participant's contact information, I telephoned the individual for a more in-depth discussion of the study and of the interview process (e.g., duration, setting, topics of conversation). If the individual was still interested in participating, I informed them that I would contact them again in the future to schedule a time to obtain written informed consent and to conduct the interview.

Consent discussions were completed in-person, with written informed consent signed on site at the QEII Health Sciences Centre at the beginning of the interview appointment.

There was one exception whereby an interview was completed via-telephone by a participant who did not wish to travel to the hospital site. This participant was mailed two copies of the informed consent form and a cover letter informing them that I would call in approximately one week to review the consent information and answer any questions they may have. During this phone call, the participant signed both copies of the consent form and mailed back one copy using the included stamped and self-addressed envelope. Once the signed consent was received, a telephone interview was scheduled.

Consent discussions outlined in detail the purpose of the study, and what participation would entail. The voluntary nature of their involvement was emphasized as well as the measures taken to ensure confidentiality and their ability to stop participation at any time, if they so wished. Following the consent discussion, and prior to the signing of the informed consent forms, individuals were asked to state the purpose of the study in his/her own words in order to ensure comprehension in the context of the research study. All individuals demonstrated an understanding of their participation and agreed to take part in a recorded interview, and were therefore able to sign the informed consent document.

Protection of Confidentiality

To protect participant anonymity, unique study identification numbers (e.g. PS01-PS13) were assigned to all documents and interview data. Only a tracking sheet documenting

informed consent links the participant's name with their unique study number.

Interviews were either video or audio recorded and all files were stored electronically and labeled only with identification numbers and the date of the recording (e.g. PS01 Interview 2011-01-01). In the one instance where an interview was digitally video recorded, the participant was made aware of the limits to anonymity associated with having their image captured.

Hardcopy research files were stored in a locked cabinet in a locked office at the QEII Health Sciences Centre. Electronic copies of documents and interview files were stored on password-protected files of a hospital-networked computer.

I personally transcribed all interview data and substituted all identifiers (i.e. names, places) with generic terms (e.g., Dr A; Location B). Transcript files were labeled only with unique study identification numbers. As per the standard procedure in Geriatric Medicine Research, the Site Investigator (Dr. Moorhouse) and the Research Manager are able to access the data files and documents containing personal identifiers via hospital-networked computers, however, to date this has not been necessary.

At the conclusion of the study, all hardcopy research files were locked in a cabinet in the office of the Site Investigator (who holds an appointment at Dalhousie University and the Nova Scotia Health Authority) on the 3rd floor of the Veterans' Memorial Building. Hardcopy files will be kept for 7 years following the termination of the study. All electronic research files will remain on the password protected file of a hospital

networked computer for 7 years and then will be deleted with the assistance of the information technology and communication systems department.

Data Collection

Interviews

A one-on-one style was chosen for interviews, versus focus group discussions. A private, intimate setting was desired to minimize discomfort and facilitate conversations delving deeply into personal matters and subjective experience. Interviews were conducted on-site at the QEII Health Science Centre in private offices within the Geriatrics department.

A semi-structured interview guide (Appendix B) was developed with input from my supervisor and methods advisor. Qualitative description is especially useful for identifying the: who, what, and how of a situation or experience (Sandelowski, 2000). Therefore, the interview questions were designed to seek an understanding of: *who* completed the program, *what* the care partners experience was, and *how* the program influenced their role as a health-care decision maker for someone else. The guide, which was slightly more structured than those generally used in other qualitative methods, served to direct the conversation and explore the participants experience as a care partner and decision maker, but also included ample opportunity for participants to share their personal story and what they felt was most important about their experience.

Interviews began with the participant completing a short demographic profile (for purposes of describing the study sample; see Appendix C). Initial questions were purposefully selected to ease the participant into the interview discussion by starting with

general inquiries about their relationship to the patient and their role as a care partner. This allowed time to develop a rapport with the individual, and for the participant to become more comfortable in the interview setting before moving on to more specific (and potentially emotionally distressing) topics surrounding their experience with PATH and acting as a substitute decision maker.

I personally conducted all interviews for this study. I was able to draw upon my previous experiences with interviewing caregivers of persons with dementia and carrying out qualitative analysis of patient/caregiver interviews to ensure open-ended questions were posed and probing questions used to stimulate detailed narratives. Clarifications were requested when ambiguous statements were made. To ensure the authenticity of the information and insights provided, I frequently repeated information back to participants during the interview, and asked them to clarify and verify the information provided.

Most interviews lasted approximately 60 minutes. At the end, participants consented to being contacted by phone if additional questions were to arise following completion of the interview (for example, if the first three participants did not spontaneously discuss a topic which became a major theme in subsequent interviews). However, follow-up phone calls were not required. In recognition of the fact that topics surrounding end-of-life care can be distressing, participants were given the option of speaking privately with a geriatric nurse or social worker at the end of their interview, or at a later date if warranted. To my knowledge, no participants required such service post-interview.

Interviews were conducted between June and October of 2011. Initially, participants were offered the opportunity to choose between having their interviews either video or audio recorded based on personal preference. Participants were also offered the opportunity to complete the interview via telephone in an effort not to inconvenience individuals who may have to arrange care for the PATH patient were they to leave home. Following completion of the first three interviews (one recorded via phone, one video-recorded, and one in-person audio-recorded) the transcripts were reviewed with my supervisor and methods advisor for feedback. At this time, all were in agreement that subsequent interviews would only be conducted in-person and audio-recorded, as the other mediums may have limited my ability to develop a rapport with the participants and to elicit free-flowing, detailed discussions.

Field notes

Field notes were recorded during the interview, including my impressions, notable gestures and facial expressions, and items requiring follow-up or clarification during the interview. Impressions and reflections were used when compiling brief participant summaries. Notations regarding gestures and facial expressions were used to provide further context during the transcription process.

Interview Transcripts

After each interview, the recordings were reviewed to ensure audibility and completeness. I transcribed all interview recordings verbatim (identifiers substituted with generic terms) into Microsoft Word documents using a free version of Express Scribe Transcription Software (available at: <http://www.nch.com.au/scribe/>). Additionally, non-

verbal communication recorded in the field notes were included to provide additional context. Accurate transcription was achieved by re-reading transcribed documents at least twice while listening to the interview recordings. Transcripts were placed into an ATLAS.ti® database (<http://atlasti.com/>) to facilitate analysis.

Participant Summaries

To promote contextual understanding during data analysis, brief, participant descriptions were created. Summaries included what was learned from the field notes, demographic questionnaires, and transcribed interview data. The participant summaries were included at the beginning of each interview transcript. These participant profiles were essential for establishing context during the coding-review process and analysis phase.

Analysis

This qualitative descriptive study of the care partner's experience of the PATH program employed a framework analysis approach. While content analysis is the most common form of analysis used in qualitative description (Sandelowski, 2000; Sandelowski, 2010) it was deemed inappropriate for this study given the specificity of the research questions posed, and the more structured nature of the questions being asked of respondents.

Framework analysis is designed for conducting applied qualitative research (Ritchie & Spencer, 2002). This approach to analysis allows for some codes to be inductively selected based on the specific research questions posed by the project, while allowing for additional codes and themes to emerge from the data in an iterative process. Framework analysis firstly involves applying an order or structure to the data by applying codes that

made the data more accessible for interpretation, to help to reduce data volume, and to prioritize questions.

Initial code development involved reviewing printed versions of the transcripts. Key phrases and topics were highlighted and comments written in the margins to record preliminary thoughts. Specific attention was placed on identifying passages describing elements of PATH framework (i.e., understanding, communication, self-efficacy) and the specific research questions posed (e.g., tools and services provided, caregiver burden, outcomes). Phrases and topics were then summarized, using the participants' own words, to create 'in-vivo' codes - which are favoured in framework analysis (Ritchie & Lewis, 2003).

After a review of the initial code development with the study supervisor and advisor, a formal coding matrix was established based on Donabedian's framework for evaluating the quality of medical care (Donabedian, 1998; Donabedian, 2005) and the Quality Health Outcomes model presented by Mitchell, Ferketich and Jennings (1998). This approach encompassed the multiple attributes that can contribute to a definition of 'quality.'

Structural codes were developed to capture the context in which the PATH program was experienced for each participant. This included the system characteristics (e.g., facilities, referral process, resources) and characteristics of the participant (and PATH patient) such as attitudes, perceptions, and previous experiences, as these characteristics formed the

context for their personal experience (e.g., previous experiences with the death and the health care system, care giving responsibilities, the values/beliefs/goals of the participant and the PATH patient).

Process codes were created to capture descriptions of the participants experience at PATH, such as, involvement of other family members, supports received, information/advice/opinions/diagnoses obtained, discussions that took place, and suggestions regarding program development.

Outcome codes were applied to all descriptions of events, attitudes, plans or reactions that were deemed to be a result of participation in the PATH program. For example, participant described impact of participation on both the care partner and the patient, decisions made as a part of the PATH process, and feelings about future decision-making.

Following the placement of a transcript in ATLAS.ti[®], the document was coded with the participant's unique study ID, sex, and relationship to the PATH patient. Next, the summary section of the transcript was applied a unique code for easy retrieval of participant overviews. Transcripts were then coded using the code list. As new themes and topics emerged, the new codes were added.

When four transcripts had been coded, the initial code list was examined to identify common themes and areas of duplication. From this review, the code list was revised to

differentiate between concepts, which I would want to describe in greater detail (i.e., structure/process/outcome codes) and the qualifiers providing additional context to these concepts (e.g., improvement and decline, negative and positive). Additionally, to gain insight into changes perceived to be a result of participation in the PATH program, timeline codes were added to capture discussion of events before, during and after PATH program attendance. Finally, 'gem' codes were added to capture sections that were particularly illustrative. The code list was then presented to my supervisor and methods advisor for input and refinement. The next three transcripts were coded using the revised coding scheme. When no additional revisions to the code list were required, the first four transcripts were then reviewed for re-coding. Finally, the remaining four interviews were coded.

Following the completion of data coding, descriptive accounts of the care partners' experiences with the PATH program were synthesized. Similarities and differences in experience were examined which led to a refinement in initial themes and categories. Secondary codes were applied to make the data more accessible for within and across-case comparisons. Finally, associations and patterns across care partners' experiences were examined to form explanatory concepts which can be used when seeking wider application of the PATH program to other populations.

Summary of Methods

This qualitative descriptive study collected data from care partner participants of the PATH program. Maximum variation sampling guided participant selection in an effort to

acquire a diverse representation of participants with differing post-PATH experiences caring for individuals with a variety of primary diagnoses (though all but one patient either had a previous diagnosis of dementia, or received a diagnosis of dementia at PATH). A semi-structured interview guide facilitated the collection of data that specifically addressed the research questions posed and also provided an opportunity for participants to share what they felt was most important about their own experience. A framework analysis approach facilitated the analysis of the specific research questions posed by the project, while allowing novel themes to emerge in an iterative process. The next chapter offers a detailed description of the care partners experience with the PATH program, and the role PATH plays in their experience as a substitute decision maker.

CHAPTER V. FINDINGS

This chapter explicates the findings of a qualitative descriptive study of the care partners' experience with the Palliative and Therapeutic Harmonization (PATH) Program, and the role PATH plays in the experience of a person caring for a frail, older adult with multiple, chronic, life-limiting conditions. The chapter begins with a detailed description of the study participants, including demographic characteristics and events leading to PATH program participation. The remaining sections of this chapter provide the description of care partners experience with PATH and the role PATH played in the experience of the substitute decision makers.

Participant Characteristics

During the study recruitment phase (July 2010-May 2011) 19 care partners (of 17 PATH patients) indicated they were interested in participating in the research study. The PATH physicians assisted with maximum variation sampling by providing insight into which potential participants would represent a diverse sample of the types of individuals receiving services from the program. All 19 individuals were approached for study participation. Four individuals either could not be reached for a more in-depth discussion about the study, or declined to participate (following the death of the PATH patient). The remaining 15 individuals agreed to be interviewed. Interviews were conducted with 13 care partners representing 11 PATH patients; 3 of whom had died prior to the study interview. By the eleventh interview it was deemed that no new topics / themes were emerging; the remaining two volunteers would not have contributed to maximum

variation sampling (e.g, had not yet experienced the death of the PATH patient) and therefore were not interviewed.

Table 2. Care Partner Characteristics

Characteristic		n=	(%)
Sex	Female	12	(92)
	Male	1	(8)
Age (years)	30-50	2	(15)
	51-70	7	(54)
	>70	4	(31)
Residence	Urban	6	(50)
	Rural	6	(50)
Relationship to PATH patient	Spouse	4	(31)
	Child	7	(54)
	Sibling	1	(8)
	Other family	1	(8)

Individuals presented to PATH having a wide range of previous experiences with the patient, the health care system, and with the experience of death and dying. Participants were receiving varying degrees of support from other members of the patient’s immediate family and/or other support persons.

Less than half of the participants had experience working in a health care, and most reported no previous experience as a care partner for someone nearing end-of-life. A small number of care partners discussed their previous experiences with end-of-life care and/or the death of a loved one. One individual described multiple experiences assisting loved ones prior to their death, saying, *“I seem to be in a position and able to help people to exit the world.”*

In all but one case, participants characterized themselves as having a healthy relationship with the patient; most voluntarily discussed areas of minor conflict and disagreement. One exception involved an individual who openly described his own issues with anger and a patient dealing with an addiction to prescription medication and eventual dementia diagnosis. In this case, the care partner characterized himself and the patient as being *“like two kegs of dynamite shoved together.”*

Only three participants described themselves as the primary care partner operating independently of any other family members. The remaining participants were navigating their role within the context of a larger family dynamic. In some cases, additional family members had minimal involvement; others considered themselves as a part of a “team” with varying degrees of care and responsibilities shared amongst family members. In three cases, only the positive influences of supportive family members were described. For others, the challenges of operating as a decision maker within the family unit were highlighted.

I feel that I have to be on the defense with [my brother] all the time to make sure that he understands I'm trying to do the best I can for our dad [PS03]

Some of them were more easy-going in letting me make those decisions and my sister has not been particularly easy going... there was a lack of cooperation. [PS10]

When [my sister] would fly into town three or four times a year all hell would break loose, everything I was doing was not right... I truly resented her coming in and thinking I wasn't capable of doing things... I knew the decisions had to be made and I just didn't want to incur any wrath from my siblings. [PS11]

When asked to describe how they felt about being a care partner and/or substitute decision maker before coming to PATH, some admitted to feeling “intimidated” by the task and “overwhelmed.” Others remained quite neutral on the topic, saying it wasn’t something they had thought about. Half of participants specifically described it as a role they naturally assumed.

I just knew I was the older child, I was here, I was the daughter...it was my thing to do. My mother brought me up; I had to see her on the down-road of life... I didn't feel like it was an obligation [PS12]

I didn't feel compelled; I just felt it is what it is... I guess I felt it was my lot in life. For me it wasn't a chore, it was something I would do for my brother, whom I loved. [PS01]

I felt it was dumped on me... but I also felt my father had looked after me all my life, the best he could, and I needed to return that to him [PS03]

Prior to receiving a PATH referral, nearly all patients had received care from multiple specialized health care providers (in addition to their family doctor). For example, one patient was being followed through the Heart Failure and Renal Function clinics; another was receiving care from Oncology, a Cardiologist and a specialized Seniors Clinic. In general, participants were happy with the care the patient had previously received, speaking highly of family doctors and specialists, especially Nurse Practitioners (from various services) who were described as readily available resources providing comfort and information. One participant focused on an emotionally charged and frustrating pre-PATH health care experiences for the greater part of the interview discussion.

For some care partners, referral to the PATH program came at a time of crisis, when high levels of burden were being experienced. For others, PATH was presented as a

resource when decision-making was required and while the care burden was relatively low. At the time of referral, the majority of patients lived at home with the care partner. Fewer lived independently, in a retirement home, or long-term care facility. Almost all patients not living in an assisted-living facility were in receipt of some type of formal home care, ranging from minimal assistance with housekeeping duties and/or personal care to daily in-home aid.

Patient referrals came from in-patient specialist physicians, the Renal Clinic, Geriatric Medicine Clinic and Falls Clinics, a Palliative Care physician, a Geriatric social worker and a Geriatric Clinic pharmacist. One care partner described herself as having a previous relationship with a PATH physician and requested the referral from the patient's family doctor. Referral reasons included decision-making for potential treatments, crisis management and end-of-life care planning.

With the exception of the participant who sought out a referral, care partners were not previously aware of the PATH programs existence. Many described how they presented to the first visit not fully understanding the purpose of the program or the topics that would be covered. For some, this lack of understanding resulted in discomfort during the initial visits, and feelings of not being prepared to complete the PATH tasks.

I think [my Dad] was a little skeptical at first about this whole PATH clinic... when you don't know about these things in the beginning you are a little skeptical. [PS02]

I was just floored by the fact that there was such a service available... we thought it was just really about dementia, a cognitive assessment that's all I thought it was, I didn't know the breadth of it. [PS08]

I said do I really need to make these decisions now, I started to feel a little bit pressured.
[PS12]

For one individual, not having a complete understanding of the program, and the intentions of the PATH team, prevented him from fully disclosing all information during the initial encounters.

At first there was a lot of things I never told them... it was a bunch of people that I didn't even know, and I don't know if I want to tell them a whole lot because I didn't know anything about the program and all I was getting was that they were gonna try to help me deal with my dad's cancer and his other problems, and that they were gonna help dad understanding some of them. [PS03]

PATH Process

Participants completed the PATH tasks over the course of two to three visits, depending on the needs of the individuals involved. Some patients continued to be followed as health status declined. Care partners reported satisfaction with how the program was delivered, highlighting their surprise at the length of time dedicated to each appointment and the breadth of information discussed. These lengthy, in-depth discussions provided the caregiver with piece of mind and a greater understanding of the patient's health and prognosis. Physicians not only assessed the patients and provide new diagnoses, but they also took the time to get to know the each patient and care partner on a more personal level, including their beliefs and concerns, and then tailored their messaging and approach accordingly.

I was really glad they sat down with me and asked me what he was like, she asked me 'what does your father like to do' and 'what does he like to eat'... I don't think anyone's ever asked me that before. [PS02]

They explained it in ways that you understood, you know some professionals can be very academically correct and all that kind of stuff, but she talked in language that we understood and was very forthright. [PS07]

It wasn't just 'do you have your affairs in order', we talked about what those affairs were. [PS10]

Lengthy discussions were made possible for care partners of patients who couldn't be left alone for long periods of time thanks to the supervision of the Geriatric Clinic staff. Most care partners appreciated being able to speak at length with the PATH team without having to worry about the patient.

They really take the time to talk to him and ask him questions and ask me questions... they stick with me and did give me the answers I was looking for... and I could sit in there and talk to them because I didn't have to worry about what my dad was doing [in the waiting room] [PS03]

In general, the flexibility of the physicians was appreciated, for example, when, discussions were suspended to allow for more support persons to be included, and home / hospital visits arranged as necessary.

I said to her, if you don't mind I'd like to stop you right there because I'm thinking my daughter should be here. We stopped right there and then. They worked around it, so I really appreciated the fact that I was able to wait until she could [be there]. [PS12]

Sometimes, in order to meet the needs of participants, multiple PATH tasks were addressed in one longer visit. In general, this approach was appreciated, however one participant recounted her siblings having a "hostile" reaction to the program following a particularly lengthy visit.

Unfortunately Mom had to wait outside while we got through the first part... I think the intention was because my brothers worked that we would try to take three periods and

work it into two, so we made sure that Mom was down in the Geriatric Day Hospital with which she's familiar, she knows the people... it was an unfortunate situation because we talked at length with [Dr. A] and there was a lot of concern after the fact expressed that Mom was left there for an hour and a half... after the fact they were somewhat hostile towards the program and the people running it. [PS10]

Completing the PATH tasks was a challenging process for care partners, they reported finding it upsetting to witness the patient undergoing cognitive assessment, discuss the issues currently being experienced at home, and answer questions regarding future care decisions. Some struggled with accepting the mortality of the patient, and that end-of-life was no longer a far-off concept. And while the outcomes of the discussions and decisions made were ultimately appreciated, following through with the care decisions was often an emotional undertaking, for example when, invoking power of attorney, transitioning the patient into a long-term care facility or declining therapeutic care options and transitioning to a palliative-only approach.

I have to say everything that we've done since the very first visit with PATH has all been, an upward battle and... finally now I'm to the point where I can relax a little bit. [PS03]

Looking ahead was a painful experience for the younger one who clearly became quite upset at the thought her parents were now in their eighties and getting older, and death is going to come at some point in the future. [PS05]

Initially I felt really overwhelmed and drained with having to make those decisions, at the time I was exhausted there was a lot going on, with all the diagnosis with my dad... but at the same time afterwards I felt relieved that I had gone through those questions and processes... it was trying it was tearful and it was hard, but also very good. [PS09]

Many participants expressed the opinion that they, and the patient, would have benefited from earlier access to PATH. It was speculated that earlier referral may have made the

patient more accepting of the program, and overall made the PATH process easier for the care partner to undertake.

I really wish my dad would have been in it earlier I think it would have, it would be more of a stepwise approach you know as far as geriatric assessment early on... it would have been helpful to have had him to have had things like that when he was more well. [PS06]

If we would have known about it sooner then I think his father would be able to accept it and understand what people are saying right now he doesn't understand he just thinks everybody's trying to run his life and take everything from him. [PS04]

A holistic approach

Many participants perceived PATH to be a “holistic” process that provided them with a broader perspective of the patient’s health, quality of life, and social circumstances; more so than any previous health care service had done. In addition to looking at the “big picture” view for each patient, the ability of the PATH team to communicate with other providers, services and resources contributed to opinion that PATH was the one service taking care of the “whole person” and having the proper knowledge and authority to provide information, advice, and ultimately assist with decision-making.

It's a holistic approach, and that's what I liked about it. It doesn't just look at the elderly person; it looks at his whole situation. [PS02]

The material explained the medical side of things, not just the way he would act, how [dementia] effects other diseases because it's all interconnected, those were things that I really found very helpful. [PS08]

You don't need a team of specialists that are each treating one aspect of the elephant, you need a couple of people that have an understanding of the complete individual, all the medical issues that are impacting the individual, and see how they add up... PATH is that vehicle. [PS10]

The reason I liked coming here was that someone was at the top of the pyramid... it was someone to oversee Mom's health... I'm so grateful that there was one person who was in charge and seemed to know everything that was going on. [PS11]

Discussing death and dying

Conversations held during the PATH process included the topics of death and the dying process. Care partners recounted details shared with them by the PATH physician regarding the illness that would eventually be the cause of death, the expected trajectory of events, and how the patient's wishes could be honored. This was a new experience for many, and in general the honesty and communication style of the physicians while broaching this emotionally charged topic was appreciated. One participant, who attended PATH with her spouse, recounted the discussion of death to be particularly uncomfortable and upsetting for her children who were only now, through the PATH process, being forced to come to terms with their own parents' mortality.

We have lived so far from our relatives that they've never had the experiences we did in my childhood of elderly relatives dying, and you're all a part of the funeral and grieving, they've not had that and so it's very uncomfortable for them... it was a painful experience for the younger one who clearly became quite upset at the thought that her parents are getting older and death is going to come at some point. [PS05]

[PATH physician] even brought up the word 'death', and I think some doctors tend to shy away from that because they don't want to upset the patient. I think at one point she even said 'are you prepared to die because you're not having this procedure?' ... it just made everything...at our level you know. We could relate to it. It was just the fact that she said it, I thought it was unique and refreshing. [PS08]

They told mom the eventuality and the path that her disease would take and what would be the cause of her death... and that she could be made comfortable when she died, there wouldn't be any pain and I think she accepted that. [PS11]

They explained that there was nothing ahead for him but pain, or a very poor quality of life. It was comforting to come from a professional that this is what to expect, and if you

cut down on his medication... I don't really want to say the word hasten, but, there was no reason for him to continue on and I didn't want him to suffer one more day than he had to. I knew I was losing him but I didn't want him to last one minute longer, and by her voicing all these things, it made me feel, not that I'm trying to get rid of him... I didn't feel like that at all, I thought what she said was in his best interest. [PS13]

Decision-making

Though not all patients were referred for specific decision-making, decision-making and care planning are key parts of the PATH model. The PATH process is designed to culminate the design and implantation of a portable, flexible care plan that will empower care partners to be effective, informed decisions makers for the patient as health issues arise.

Prior to PATH, some participants had not recognized (or accepted) that the patient no longer had decision-making capacity. These individual required the support and encouragement of the PATH team to take on the role of substitute decision maker. Many care partners admitted that they would have avoided discussions about future care planning were they not introduced by the PATH process.

They had to kind of make him realize that his father's not capable enough to [make decisions]. [PS04]

I was asked 'what would you think if this happened?'... I guess it made you deal with some things that you probably otherwise would have put at the back of your mind. [PS05]

The majority of care partners characterized themselves as having a general idea of the patient's wishes before attending PATH. Some were aware they had been designated to

have Power of Attorney and discussed having an insight into the patient's wishes based on previous statements and decisions made.

He had made it clear to a specialists... he was asked 'if we operate and find cancer we're going to have to do a major operation or, we can leave things as they are', he said 'leave things as they are, I want to die a natural death', so I knew. [PS05]

During PATH, each care partner was provided with a Medical Decision Record. The record summarizes the discussions about appropriate care / treatments and acts as a reference tool for care partners and health professionals as health status changes and further medical decision-making is required. The decision record covers multiple potential interventions including artificial respiration, hydration, surgery (e.g., in the event of a hip fracture or bowel obstruction) and administration of antibiotics.

Each participant spent a significant amount of the interview recalling the decision points reviewed using the PATH Medical Decision Record, and the prognostic information provided during the discussion. They also readily offered up descriptions of their own decision-making process, which utilized information about the risks and benefits of treatment.

We got to the part where, what will happen if he gets pneumonia - do you administer antibiotics, what happens if he breaks a hip – do you repair it... I'd never considered that stuff...I never thought of all the other health issues that could come up [PS10]

Our decision was not to have surgery... I didn't think that his body would survive because they explained to me what the danger of him having surgery at his age and with his health the way it was. [PS03]

They were difficult questions, you think pneumonia could go away but if you put with it he's hospitalized for long periods of time and he gets pneumonia, would you treat that. [PS09]

As a result of the PATH process, care partners reported their own perspective shifting from the immediate health situation to a new, broader picture of the patient's health and quality of life. Care partners spoke frequently of the 'new' things they had to think about, including questions they previously would not have considered, and new ideas to incorporate into their decision-making. One care partner stated that it provided her some validity in how she chooses to approach the process.

It broadens your mind... you want him to have a good quality of life at this stage because you know his medical conditions are pretty serious. [PS06]

I didn't even know enough to ask the questions, it's not the answers that so important, it's the questions you ask. [PS07]

With a new, more complete, understanding of the patient's current health and disease trajectory, and knowing the questions to ask regarding potential treatment outcomes, care partners made it clear they had more confidence in the ability to make treatment decisions.

If it's a situation where you have to make this decision, and these are what you have to decide from, then yes, I'm capable of making that decision on his behalf. And I think that I would do what he would want me to do if he was in his right mind... I wouldn't have been able to do that before PATH. I wouldn't have been able to make that decision. [PS03]

They've given me some confidence in what the right thing is going to be for him...just about everybody I've talked to has made me feel that I'm on the right road, confident in the decision I would make in a certain situation. [PS06]

Saying "no"

Many care partners expressed that they would now feel comfortable (and confident) with making the decision to decline a medical intervention. Most participants indicated that

they previously had not considered “saying no” to offered treatments as a valid option.

Some expressed regret at deciding to proceed with interventions in the past.

We just assumed [dialysis] would happen. [PATH physician] said that we didn't have to listen to the doctors per se, it was our responsibility to make that decision for Mom and gave us the power to say 'no' ... we didn't know we had that power before. [PS08]

It was a bit of a shock at first, the part where [PATH physician] explained that there would be other procedures that the hospital would suggest...that was a big realization to me that oh, I'm going to have to make decisions as they come... and it's ok to refuse them, it's all a part of the process to refuse them. [PS12]

Despite the fact that these conversations about future medical treatments and care preferences were described as being “difficult” and “scary”, participants reflected positively about the process and recommended that the PATH Medical Decision Record document and conversations continue to be kept as a key part of the program.

Initially I was overwhelmed and drained with having to make those decisions, I was exhausted...but I think you should keep [the Medical Decision Record questions]. They were hard at the time... but they were extremely helpful. [PS09]

Lifting the burden

Care partners demonstrated how the PATH process ultimately contributed to a lessening of the emotional and psychological burden associated with providing care to a frail, older adult. Major aspects of the relief described by care partners related to an improved ability to “cope” with their role, for example, because of an improved understanding of the patient's illness, increased confidence in their decision-making ability, reassurances received from a trusted medical professional, access to new resources (e.g., a Wandering Registry for dementia patients) and immediate changes initiated by the PATH team (e.g., medication changes, reduction in routine health care visits/testing).

All I can describe for you is the pressure that lifts off your shoulders after you've discussed with them, and they help you understand. It's a great release...just to have somebody there to say 'oh, I understand what you're saying and we need to get you the help you need with that particular part of it. [PS03]

It's calmed me... sometimes I used to be almost panicked because you don't know what was what... so I think I've got a better grip on this health. He's pretty frail but at least I know where he stands. [PS06]

[PATH Physician] said 'no need for any more tests or doctors appointments'... and that was a huge relief because I thought I just can't go through that every month. [PS12]

Three participants specifically mentioned how their participation in PATH resulted in reduced feelings of guilt, both about the decisions being made and their ability to dedicate time to the patient and their care.

It has helped me with my guilt complex which is very good. I wouldn't want to do something and then feel guilty, like putting Mom in a home. [PS08]

The reality is I can't care for my dad myself... and do I want to? I'm not sure. I don't think I could do that in my life right now, and maybe that's a selfish thing to say but I think they also say that's it's not realistic, so I think it makes you feel less guilty by going through that PATH process. [PS09]

In addition, there was reassurance related to the fact that the care partner perceived the PATH program as a “lifeline” to reach out to in the future.

I feel like I'm not free falling. I have that support, that guidance. Having a little talk and feeling empowered and feeling I have the energy to deal with it, and maybe dealing with the situation in an entirely different way, with a lot less angst. [PS10]

It gives you peace-of-mind, it's like a lifeline to lean on. [PS13]

PATH to End-of-Life

A subgroup of three care partners continued to receive the support of the PATH program over the course of the patient's death. For two patients, death occurred at home (in

accordance with the patients' wishes); the third died in-hospital. Each participant was able to reflect upon how their involvement with PATH may have impacted their experience with the dying process.

Care partners described their experience witnessing the process of the patients passing as extremely difficult. One participant described the final stages of a home death saying, "*it was horrifying... my brother was beside himself, he was spinning like a top, my sister was sobbing... it was pretty horrible.*" [PS12]

While the physical passing of the patient was described as traumatic, the only expressions of regret about the decisions made, or the patient's experience, pertained to situations prior to involvement with PATH. Following completion of the PATH tasks, participants expressed confidence in the how they handled the process and consolation in feeling they provided their loved-one with quality care, comfort, and a peaceful death. Gratitude was expressed for having had PATH as a resource during the difficult time, whether by facilitating the logistics of keeping the patient at home, providing insight into what next to expect in the process, or simply providing an honest assessments and reassurance throughout the patients terminal trajectory.

There were no crises because the PATH clinic knew what was going to evolve in the state of health so they were able to head off any crisis. I would have assumed it would be a crisis but the decision was made beforehand of what had to be done at any one time, they had laid out the plans for what would happen. I just couldn't have done it without them... I really feel PATH prepared me for it... [Mom] knew the time had come and she didn't want to suffer and she wanted to be with her children. She didn't want any other help, she didn't want any doctors, she didn't want anything else done and she was able to die that way because of the PATH clinic. [PS11]

I suppose we never really thought about it, if he would die at home, but when the decision came up I did not mind him dying at home... I'm absolutely thrilled, it's something that gives me comfort that I was able to keep him home. If we hadn't had that care, that reassurance, if it hadn't been for PATH I wouldn't have know if we were doing it right or whatnot, if we gave him medication too often or not enough. [PS13]

Lasting Impressions

Each participant presented to PATH with a unique background and differing challenges and prognoses to understand and progress though. The flexible framework of the PATH process, and the person-centered approach of the PATH team, resulted in participants expressing favourable opinions about the program, despite the process being perceived as emotionally challenging and difficult to complete.

Early in the interview process, each participant was asked how they would describe what happens at PATH to someone in a similar situation to their own. Patients also spontaneously offered up such general descriptions of PATH throughout the interview process. The following quotes represent the diverse responses provided by participants, and illustrate the multi-faced nature of the program, and how each individual perceived the overall process and outcomes of receiving care from such a health service.

It's an opportunity to sit down with your family members, with your Geriatrician that is aware of your spouse's health history. And at this meeting they can tell you what are the likely health care decision points that may be ahead... and as a family, the doctor can help you decide what do you think would be the best decision, with your spouse being involved in that too. [PS05]

It's not so much that PATH helps the patient, it helps the family deal with the patient. [PS08]

I really think the whole process has just helped me understand what's going to happen, what to plan for and what to expect. [PS09]

I'd say they smooth the waters, they make the transition into the next stage of life, the decline, so much easier to accept and to handle. [PS11]

It's palliative and treatment harmonization, it helps you deal with two or three different issues at the same time, whether they be terminal or not... it just gives you some guidance, they would have all the information on your husband, probably things you didn't even know. [PS12]

CHAPTER VI. DISCUSSION

As described above, participants in this study were care partners and surrogate decision makers for frail, older adults with multiple-co morbidities. Most PATH patients had a prior diagnosis of dementia, or received the diagnosis as part of the PATH assessment, and thus represent a population often not in receipt of appropriate palliative care services (Canadian Institute for Health Information, 2007). As such, these care partners and patients represent a group that might not otherwise have interacted with provincially available end-of-life services until much later in the dying process. PATH provided education on co-morbidities and prognosis, decision-making tools, on-going consultation, and direct patient care during end-of-life. This is in contrast to provincial palliative care programs, which are designed primarily as consultation services and predominately provide care to patients dying of cancer (NELS ICE, 2008).

Participants described their PATH experience as ‘holistic’; fully involving the care partner in a process that encompassed the patient’s personal wishes, the needs of the care partner (including emotional support), and also the input of extended family and informal care providers. In addition, it was perceived to provided a communication link between other subspecialty services, and, in some instances, act as the primary care service at end-of-life.

I notice they seemed to be pretty well connected with his other caregivers [sic: health care providers], just this morning they picked up the phone and called [specialist clinic]. They seem to pull together the information; they communicate with each other so it not just that one does an assessment and the other one doesn't know about it. [PS05]

This chapter discusses care partner experiences with the PATH program within the context of the literature. Overarching themes are presented from the each of the three attributes of quality medical care (Donabedian, 1998; Donabedian 2005; Mitchell et al., 1998). The structural theme ‘Not Prepared for the PATH’ explores the context of program referral and initial reactions to program participation. The process theme ‘Difficult Conversations Pave the Way to a Better Understanding’ describes the program delivery including the emotional challenges associated with receiving information about the patient’s health and prognosis as well as the surrogate decision-making processes. Finally, the outcome theme, ‘A PATH to Self-Efficacy’ summarizes the impact program participation has had on the care partners comfort and confidence in their role as a surrogate decision maker. As these themes are explored potential areas for program enhancement are discussed to inform clinical practice within the PATH program. Limitations of the current study and directions for future research are highlighted.

Structural Theme: Not prepared for the PATH

Feedback suggests that most participants begin the PATH program without an adequate understanding of the goals and scope of the program. For example, one participant reflected back on her initial experience, saying:

I don't think when I went in there I was prepared to answer all the questions... I just didn't really know too much about it and maybe if I would have had a little more information about the clinic it would have been helpful. [PS09]

This lack of initial understanding of the program has also been reported in quality-assurance interviews (Moffatt et. al. 2016) and, as demonstrated in this study, can prevent full disclosure of concerns until a rapport is developed with the PATH team.

Feelings of being ill-prepared may be multifactorial. First, the program was relatively new at the time this study took place, and as such the referring clinician may not have had a sufficient understanding of the PATH program in order to manage patient and caregiver expectations. The Clinic staff responsible for booking appointments would similarly have had little background knowledge of the program, and therefore may not have been able to provide any additional details during the visits booking conversation. Prior to the first visit, an Introduction Letter was mailed to the patient participant. This letter outlines what to expect from the first PATH visit, however, there is no way to ensure such materials were reviewed or understood by the patient or caregiver prior to the first encounter, especially in consideration of the high number of PATH patients with cognitive impairment. Given that many individuals are reluctant to broach the subject of end-of-life (Black et al. 2009) it should not be expected that any pre-visit communication would be able to fully prepare participants for the challenging tasks involved with the PATH process. However, institution of a new pre-visit communication strategy to both the patient and care partner(s) may better prepare participants, which could possibly shorten initial visit length and allow for resources to be re-allocated to additional clients.

Interestingly, despite the fact that PATH aims to serve as an early intervention program for frail older adults who would not usually qualify for end-of-life focused health care services, care partners expressed regret that the patient's referral did not come earlier. It was postulated that an earlier referral (e.g., prior to significant cognitive deficits) would have allowed the patient to participate in, and better appreciate the PATH process. In the time since this study was conducted, PATH has advertised with Doctors Nova Scotia to

encourage family doctors to refer their patients. Improved communication and engagement with primary care can help to facilitate more timely referrals, before the later stages of frailty and cognitive decline are reached and health crises requiring decision-making are required. Receiving a PATH referral from primary care, rather than a subspecialists with whom the patient / family may have had limited time to develop a rapport with, may also help to alleviate care partners' initial feelings of being unprepared for PATH. It may be easier for patients and care partners to be introduced to the idea of an end-of-life service such as PATH by a health care provider with whom they are familiar, potentially have developed a trusting relationship with, and with whom they may feel more inclined to question about the details of the service and reasons prompting the referral. A primary care setting may also be a more comfortable setting to introduce and end-of-life service because patients and care partners may feel more at ease in the primary care office than a hospital-based, subspecialist clinic.

The design of the PATH process, often spanning three visits with continued follow-up, appears to allow ample opportunity for in-depth conversation. Care partners reported their satisfaction, and even surprise, with the amount of time afforded for each visit. There were no reports of feeling rushed; participants indicated that they had received adequate time to convey their concerns and have their questions answered. However, the generous in-clinic visit length presented a challenge in situations where either the patient was not capable of participating fully in the PATH tasks due to cognitive impairment, or, when extended private interviews with only the care partner were required to share information about current health status or facilitate private counseling. In such cases, the

patient may be left alone for an extended period while care partner(s) meet privately with the PATH team. Adequate clinic staffing and support during this time is essential, and was appreciated by most participants. However, as illustrated in one case, it can be disconcerting for a care partner to be separated from the patient for a length of time, especially if the individual is not familiar with the clinic or the clinic staff, and if the patient is not able to safely stay by themselves in the waiting room. This sentiment was also shared via the informal exit survey completed by the first cohort of PATH participants (Moorhouse & Mallery, 2012) where it was recommended that session time be shortened when individuals with dementia are present. When the capacity for the clinic to provide alternate arrangements during this separation is not deemed sufficient, visit length can then be perceived as a negative aspect of the program design.

Additional flexibility with regards to the number of scheduled encounters may be required in order to reduce visit length. For example, in some cases it may be more desirable for patients and care partners to visit the clinic on separate occasions during the initial assessment phase, or for the care partner to return to the clinic alone when additional background information is required or extensive care partner counseling / guidance is necessary. However, more frequent visits may not be appropriate for all clients, especially for those with limited access to transportation or lengthy travel-times, as well as those who would need to arrange alternative care for the patient while they attended the visit. A pre-visit communication strategy may serve to improve care partner experience by affording the opportunity to indicate a preference for lengthier, or more frequent, PATH encounters.

Process Theme: Difficult Conversations Paving the way to a Better Understanding

According to study participants, and as outlined in steps one and two of the PATH process, a shared understanding of current health and terminal trajectory was established early on. This is the first step to achieving appropriate end-of-life care (National Consensus Project for Quality Palliative Care, 2009). Yet, this is often not achieved in current medical practice (Cherlin et al., 2005). Participants described the process of receiving information about the patient's current health status, prognosis and potential future health care decision points to be arduous and emotionally challenging. Many respondents (63%) of the informal PATH exit survey also reported finding the PATH process upsetting (Moorhouse & Mallery, 2012).

During these lengthy discussions, details were effectively communicated to the patient and the care partner, including disclosure of diminished decision-making capacity, honest descriptions of the terminal trajectory, and discussions of the dying process. Care partners also received new information from the patient about their care goals, values, and preferences.

It's almost like a secret, what's going to happen when you die. People don't talk about it, and it was talked about.... 'what are your wishes?' and she had written down in her little black book what she wanted but she hadn't told us her wishes, we didn't get that depth of conversation and it's a weird conversation to have. [PS11]

Conversations about end-of-life can be difficult, and many individuals are reluctant to think about, let alone discuss, hypothetical scenarios and preferences (Black et. al, 2009; Carrese et al., 2002). Care partners in this study expressed their reluctance to discuss such topics, and described PATH conversations as challenging. For example, one care partner

described the process as *“trying and tearful”* and, reflecting on her experience said, *“I was drained, it was tiring... all the questions are emotional.”*

Many participants admitted that the difficult conversations regarding future care planning and decision-making would most likely have been avoided had they not been facilitated by PATH. In the time since these care partners completed the PATH program, Nova Scotia has been working to enhance palliative care services with an Integrated Palliative Care Strategy (Nova Scotia Department of Health and Wellness, 2015). This strategy includes engagement of patients and families, and the development of palliative care and advanced care planning resources. It is not known if these strategies have increased the number of participants who present to PATH having already started these discussions (either on their own, or facilitated by another health care provider) or resulted in reduced feelings of discomfort with PATH-facilitated end-of-life discussions.

Ultimately, participants reported that while the PATH discussions were painful, and the information hard to receive, the result was an improved understanding of the patient’s goals of care, their health status, and how the concepts of frailty and dementia should be incorporated into future health care decisions. This is consistent with exit survey reports from the first cohort of PATH participant dyads (Moorhouse & Mallery, 2012). Here, participants were able to effectively illustrate how the information received through PATH had improved their health literacy. Rarely did a care partner mention the use of an Advanced Directive; a commonly used legal document for specifying future care wishes. Instead, participants repeatedly referred to the conversations with the PATH physician

where the PATH Medical Decision Record was explored. This document is used to guide conversations about potential future health crisis events (including implications of withholding and administering treatment) based on current health status and prognosis. Individualized preferences can then be recorded and kept on the patients chart for future reference. When recounting these conversations and potential future care decisions, participants spent time discussing the concepts of frailty, dementia, and quality of life; less emphasis was placed on the details of specific medical interventions that would or would not be desired (as is often recorded in an Advanced Directive). It would appear that the PATH method avoids the commonly documented pitfall of Advanced Directive statements, which have been criticized for being either too vague or too specific for application during a health crisis. (Carrese et al., 2002; Black et al., Forbes et al., 2000; Rosenfeld et al., 2000, Perkins, 2007). Instead, care partners were able to employ substituted judgment (a preferred method for substitute decision-making) (Emanuel & Emanuel, 1992) by objectively considering the pros and cons of potential decision points, with a focus on how a treatment or procedure would impact quality of life and ensuring the patients values and goals of care were respected.

I have to consider what his quality of life would be, with getting some facts about what his chances are of recovering, and what his life is going to be like after. [PS06]

All but one participant in this study was a care partner for an individual diagnosed with dementia. Further research would be required to determine if care partners of non-dementia patients demonstrate similar use of substituted judgment when discussing potential medical decision points. It highly likely that the care partners of persons with cognitive impairment are significantly more involved and invested in this aspect of the

PATH process due to the patients impaired decision-making capacity. The care partners of non-dementia patients may have a much different experience during the Decision Making Record exercise, as the patient would likely be the more active participant in the discussion.

Thompson (2006) has described patient involvement in health care decision-making ranging from non-involvement to autonomous. Smebye et al. (2012) have expanded on this model to include two additional levels in the context of cognitive impairment: pseudo-autonomous and delegated decision-making. It is somewhat challenging to apply Thompsons (2006) and Smebye's (2012) models to the involvement of PATH care partners in making decisions for, and with, the PATH patient. Ultimately, the design of the PATH program aims to provide patients the opportunity to select a delegated decision maker who will be responsible for making decisions on the patients behalf in a health crisis, and to adequately equip this individual with knowledge of the patient's values and goals of care so that informed decisions, in line with patient preferences, can be made. However, the delegates themselves will have individual preferences for their own level of involvement in making decisions with the health care provider (i.e., the four levels described by Thompson (2006)). Further work is required to examine if surrogate decision-making can be added to these models, or if these models should be 'layered' over a separate surrogate decisions-making framework.

Research indicates that decisions made by surrogates are often not in agreement with patient preferences (Fried et al., 2003; Moorman & Carr, 2008; Zikmund-Fisher et al., 2006), especially when dementia is present (Ditto, 2001). This study did not specifically

examine if decisions made by care partners following PATH participation were in alignment with patient preference. Future research could examine the participation of the care partner and patient in the establishment of the care plan, and the execution of that plan by the care partner at end-of-life. Additionally, the experience of care partners using Advanced Directives could be compared to those afforded the opportunity to facilitate decision-making using the PATH Medical Decision Record.

Anecdotal reports from PATH physicians indicate that care partners often require support to process emotions of grief and loss after receiving prognostic information and struggle to accept the changes in the patient, their relationship with the individual, and ultimately, the terminal prognosis. However, despite the fact that anticipatory grief is a well-documented component of end-of life decision-making (Meeker & Jezeqski, 2009, Wendler & Rid, 2011) this topic was not well described by the PATH care partners. It may be that the participants who agreed to participate in this study experienced less difficulty with accepting a terminal prognosis and / or were naturally inclined to focus on the more positive emotions they experienced in their role (e.g., relief, empowerment). Alternatively, lack of discussions about negative emotions associated with receiving information about a terminal prognosis may be due to the study design. The research questions did not specifically address this topic, and the interview guide was not designed to focus on understanding the caregiver's experience of accepting the functional and relational changes associated with the patient's terminal trajectory. This highlights a potential area for further research, which could be useful in informing future modifications of program delivery for clients requiring additional emotional supports.

Outcome theme: The PATH to Self-efficacy

A major theme emerging from descriptions of PATH participation was the outcome of self-efficacy. In addition to demonstrating *how* they would carefully consider medical decisions, care partners described a newfound comfort and confidence in their role as a care partner and surrogate decision maker. All but one participant was a care partner for a person with dementia; as such it is not possible to determine if care partners for patients without dementia would similarly place an emphasis this outcome of participation. However, improvements in decision-making self-efficacy have similarly been reported on in a thematic analysis of randomly selected quality-assurance interviews conducted with PATH care partner participants (the proportion of care partners for persons with dementia is not reported on in this study) (Moffatt et al., 2016). Further work is required to determine if care partners of non-dementia patients demonstrate similar feelings of confidence when it is time to take on the role of surrogate decisions maker.

In this study, care partners demonstrated decision-making self-efficacy via descriptions of the decisions they had, or potentially would have, to make.

I am the one that calls the shots, and I have the support that I need and I'm confident that I'm making the right decisions. PATH doesn't make the decision for me, but PATH gives me the information and helps me define what my responsibility is, and not to be afraid to make the judgment calls when they have to be made. [PS10]

Self-efficacy was especially evident in the realization that proposed medical interventions could be declined, and that rejecting a treatment can ultimately be in the patient's best interest. This is in contrast with the current literature which shows that surrogate decision makers have a tendency to over-emphasize patient preferences for life-sustaining treatments (Moorman & Carr, 2008; Zikmund-Fisher et al. 2006). Such over-

treatment decisions can be due to a fear of not doing enough, and a desire to feel that everything possible has been done (Chambers-Evans & Carnevale, 2005; Moorman & Carr, 2008).

For the care partners in this study, the ability to decline treatment provided a relief to those with concerns about the prospect of putting the patient through treatments and therapies in the future. These comments suggest that the PATH process can effectively achieve the goal of helping to prevent over-medicalization of the dying process by improving surrogate decision-making self-efficacy. Moorhouse and Mallery (2012) have reported a reduction in the demand for offered interventions (especially for those with higher baseline frailty and late-stage dementia) following completion of the PATH tasks. The findings from this study provide insight into the mechanism by which PATH participation results in proposed medical interventions being declined following careful consideration of potential risks and benefits.

Interestingly, care partner descriptions of saying ‘no’ implied that declining a treatment would potentially mean going against what was being offered or recommend by another health care provider. For example, one care partner said:

Some doctors can be pretty aggressive you know, and say ‘your mother should do this’... [PATH Physician] gave us the ability to question that and to say ‘no’ and to be Mom’s advocate for quality of life...and the ability to make those decisions without feeling like we’re shortening Mom’s life or doing anything detrimental to her health. [PS07]

These comments suggest that care partners perceive the PATH approach as being in conflict with the methods and recommendations of other health care providers. It is not

known if this opinion is shared by subspecialty referral sources, or if empowering care partners in this manner has an impact on the likelihood of subspecialists to refer patients to PATH.

For the surrogate, end-of-life decision-making, especially the decision to withhold treatment, often involves significant stress, anxiety, guilt, doubt and grief (Meeker & Jezewski, 2009; Wendler & Red, 2011). These feelings are reduced when the decision maker is confident in their understanding of the patient's wishes (Wendler & Rid, 2011). While participants in this study used negative qualifiers to describe the emotional process of completing the PATH tasks they did not convey feelings of excessive doubt, grief or general emotional strife when reflecting on the decisions they had made. Even those care partners who had experienced the death of the PATH patient presented themselves as being satisfied with how they executed their responsibilities during end-of-life.

A meta-synthesis of surrogate decision maker experiences with withdrawing life-sustaining treatments reveals that individuals generally experience both negative (e.g., trauma and burden) and positive (e.g., fulfillment and empowerment) outcomes (Meeker & Jezewski, 2009). Having confidence in such end-of-life decisions has been shown to influence the surrogate's ability to move on in a positive way following the death of the patient. The PATH process, by providing information and support, appears to improve surrogate decision-making self-efficacy and as such serve to reduce decisional doubt, feelings of guilt or regret, and the trauma often associated with surrogate decision-making.

The current PATH model allows for continued engagement following the completion of the PATH tasks, and care partners routinely engage the program in times of crisis (Moffatt et al., 2016). It is important that the continued support of PATH not be overlooked when examining the outcome of self-efficacy. While these individuals were able to astutely demonstrate their improved health-literacy and decision-making capabilities, the connection with the PATH clinic (e.g., PATH as a “lifeline”) significantly contributed to the care partner’s confidence.

The comfort it gives you as the caregiver who’s going to be asked the questions... here is someone you can go to and have full confidence in. [PS05]

The positive effect of shared decision-making between the health care provider and the surrogate, and the surrogates’ perception that they are being supported has been reported (Heyland, 2003; Tilden, Toile, Garland, & Nelson 1995). In order to continue fostering positive surrogate outcomes, it is of utmost importance that this model is sustained in future iterations of the PATH to ensure that participants do not ‘graduate’ out of the program prematurely.

Three participants (representing three PATH patients) were able to speak to the experience of receiving end-of-life support from PATH during the dying process. One participant reflected upon the support she received while making decisions during the death of her brother, saying:

I still feel to this day that we made the right decision about [Patient]. [PATH physician] helped me to see there was no.... progress. She helped me through it, she tried to help me

make intelligent decisions, we made it, and I had told her how I felt and she just respected my wishes.[PS01]

These three individuals had no previous experiences with death or the dying process; as such, no comparisons can be made between the experiences of death with / without PATH involvement. Further examination of the care partners experience of receiving PATH support at end-of-life is required to determine how support and clinical care from PATH impacts care partner and patient experiences with the dying process.

Study Limitations

As a researcher involved in the development of PATH materials I ran the danger of being bias towards participant impressions of the program. The lengthy delay between the data collection (2011) and data analysis (2016-2017) allowed me the opportunity to distance myself from the PATH program and the study data, and helped in allowing me to recognize and adjust for personal biases. Having an advisor, Dr. Emily Marshall, critique my findings served as an additional check on bias.

As with other examinations of participant experiences (Moffatt et al., 2016), participants in this study reported high levels of satisfaction with PATH; few individuals provided negative narratives or program critiques despite the interview guide specifically asking: “If we were going to make changes to this program, what would you recommend we change?” and prompting for descriptions of barriers to participation. While it may be that most participants have positive experiences with PATH, it should be acknowledged that selection bias of the inclusion criteria excluded the voices of participants who chose not to complete all three PATH tasks. As such, this study cannot speak to the experience of

those who decline additional PATH services following the initial assessment or the discussion of health status and prognosis.

It may be that the PATH process, and current clinicians, are not adequately equipped to serve clients who are less accepting of information regarding a terminal prognosis, and therefore not able to proceed with the shared end-of-life decision-making process.

Exploring the experience of these participants may provide insight into the types of individuals who are less likely to benefit from the service (and ensure resources are allocated to those most likely experience positive outcomes) and inform any program modifications required to better serve populations not currently benefiting from the PATH approach.

Despite the fact that maximum-variation sampling was desired, the majority of participants in this study were care partners for PATH patients diagnosed with dementia. This is closely representative of the patient population at PATH; 90% in this sample versus 70% in a study of the first 150 PATH patients (Moorhouse & Mallery, 2012). Care partners were not selected based on this criterion; the diagnosis of dementia was often not evident until the interview visit when a demographic profile was completed (Appendix C). This slightly higher percentage of dementia care partners may be a result of the types of patients being referred to PATH during the recruitment phase, which occurred when the program was a relatively new service. Self-selection may also have played a role; care partners of individuals lacking decision-making capacity may have felt a better connection to the PATH process due to their greater level of participation (e.g.,

sometimes completing PATH tasks two (*Communicate*) and three (*Empower*) without the cognitively impaired patient) and therefore were more inclined to share their experience.

This study is not able to speak to the experience of care partners for patients with decision-making capacity. Interviews were conducted with 13 of the 15 care providers who volunteered to participate; a larger sample size may have allowed this study to compare the experience of care partners for dementia patients with those of non-dementia patients. Future research should explore the experience and outcomes of PATH care partners who do not take on surrogate decision-making responsibilities until after the PATH tasks have been completed. Such work may help to identify how to optimally engage care partners in the process when the PATH patient is able to participate fully in the care planning process.

This study provides limited insight into the experience of care partners receiving clinical care and support from PATH at end-of-life; only three care partners had experienced the death of the PATH patient at time of interview, and more than one volunteer ultimately declined to be interviewed following the death of the patient (it is not known if PATH care was received during these deaths). Future research should examine in greater detail the experience of care partners following the death of the PATH patient to provide insight into the clinical and emotional supports provided by PATH at end-of-life, and to determine if PATH allows patients die in their preferred location more than usual care. Additionally, the perspectives of those who choose not to engage the support of PATH

could be examined to provide insight into why some care partners do not contact PATH when a health crisis occurs.

Summary and Recommendations

The PATH process was created to address the challenges associated with caring for a frail, older adult within the current health care system. The purpose of this qualitative description study was to explore how PATH is experienced by care partners, and to describe the perceived impact program participation has on the overall experience of caring for an older adult nearing end-of-life. While other works have reported on the satisfaction of care partners (Moorhouse & Mallery, 2012; Moffatt et al., 2016) this research provides greater insight into the mechanisms by which satisfaction is achieved, and the difficult process care partners must endure prior to developing feelings of gratitude and appreciation for the PATH service. These findings should be interpreted with caution; due to sample bias, this study is only able to speak to the experience of PATH participants who are care partners for an individual diagnosed with dementia.

At PATH, care partners participate in emotionally challenging discussions with a specialized health care provider. Through participation in these conversations, care partners develop improved understanding of the patient's current health, prognosis, and end-of-life care preferences. This understanding serves to foster decisional self-efficacy and role satisfaction. The care partners who participated in this study appreciated the information and support received through the clinic, perceived themselves as better able to cope in their role as a caregiver and decision maker for a frail older adult with

dementia, and felt better able to honor the patient's values and goals of care at end-of-life.

The results of this study are intended to provide insight into the strengths and weaknesses of the program so as to ensure appropriate resources are allocated to the most beneficial aspects of PATH, and to identify potential areas requiring modification as future training materials and adaptations for additional health care settings are developed. Based on reports of being unprepared for the content and structure of the clinic visits and the PATH tasks, it is recommended that the current pre-visit communication strategy be modified to improve patient and care partner understanding of the PATH model, as well as the anticipated emotional challenges associated with completing the program tasks. Resources should continue to be allocated to allow for in-depth information sharing between participants and the health care provider, and to ensure sufficient time is allocated for decision-making discussions with the Medical Decision Record. The process of completing this record appears to not only contribute to improved health care decision-making (i.e., reduction in planned medical interventions; Moorhouse & Mallery, 2012) but may also contribute to the improvements in self-efficacy and decision-making satisfaction demonstrated by these participants. Finally, it is recommended that future adaptations of the PATH model ensure that the patient and care partner continue to be supported following completion of the three PATH tasks. In this way, patients and care partners can fully benefit from receiving support from the PATH team through the dying process.

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Appendix A: Participant Recruitment Letter



Understand • Communicate • Plan • Empower

July 12, 2010

Dear Caregiver or Substitute Decision Maker

We would like to invite you to participate in a research study to evaluate the effectiveness of the PATH program from the perspective of caregivers and substitute decision makers. We would like to hear about your experience with PATH to ensure that we are delivering the information, tools and support you need to make informed health decisions for the person you care for.

Your participation in this study is voluntary and would involve one additional visit to the clinic. During this visit you will be interviewed by a researcher about your experience with PATH. The interview will take place at a mutually agreed upon time and date following your final PATH visit. If you are not able to return to the clinic for an additional visit, arrangements can be made for you to participate in a telephone interview. We will do our best to ensure that your participation is as convenient and comfortable for you as possible.

The information gathered from this study will help us to evaluate and improve our program.

If you are interested in participating in this study, check “YES” below and hand this form back to a member of your PATH health care team. Your contact information will then be given to Laura Hamilton, the researcher who is conducting this study.

YES I would like more information **NO** I do not wish to be contacted

name: _____ phone #: _____

email: _____

If you have any questions about this study, please contact **Laura Hamilton at 902-473-7295 or laura.hamilton@dal.ca**.

Sincerely,

The PATH team

Appendix B: Interview Guide



Understand • Communicate • Plan • Empower

Interview Introduction:

Hi [X] my name is Laura and I am a Dalhousie graduate student. I am conducting this research study as a part of my thesis project. Thank you for agreeing to participate today, and for allowing me to [audio](#) or [video](#) record our conversation.

I'd like to understand what it was/is like for you to care for [X] and how you feel about your experience with PATH. You don't have to answer any of my questions if you don't want to and if you wish we can stop our conversation at any time.

Question Guide:

1. I'd like to start off by having you tell me a little about your day-to-day life as a caregiver
 - Tell me about who you are and what your relationship is to [X]
 - Would you say you are the only care provider for this person, or are there other family members, friends, formal care providers involved?
2. Tell me a little about your health care experiences with [X] before you came to PATH?
 - How well you would say you understood their health conditions
 - How well did you understand how their health would change in the future?
3. How did you feel about your responsibility as a caregiver and health care decision maker before you came to PATH?
 - Did you and [X] ever talk about health care plans for the future?
 - If no, would you say you had any indications as to how they would want their care handled
 - If yes, tell me a little about what you talked about
4. Now I'd like you to think about your experience with PATH. If you were describing PATH and what happens at the PATH clinic to someone in a similar situation to yourself, how would you describe it?
 - Can you tell me what happened at your clinic visits?
5. Think back to the conversations you had with your PATH physician and the nurses and the information you were given and tell me a little about what was most useful or helpful for you
 - Information (written communication)
 - Was it easy to understand?
 - Too much or too little?
 - Strategies
 - What did that lead to?
 - Advice (verbal communication)
 - How did that make you feel?
 - Was there enough time to ask all the questions you had
 - Were there things you didn't get to discuss that you would have liked to?
 - If so, what were those things?
6. Before you came to PATH were you considering any specific treatments or procedures for [X] that you were uncertain about?
 - Were the PATH physicians able to help you make a decision

2010/10/05

7. Thinking back to how you used to feel about making medical decision for/with [X] before, would you say PATH has made you feel differently about that role now?

- Do you think you have a better understanding of their health
- Do you think you have a better understanding of their wishes
- Do you think you have a better understanding of the questions you should ask when a medical issue arises?

8.A - ONLY TO BE ASKED IF PATIENT IS NOT DECEASED

How are you managing today with your role as a substitute decision maker?

- Have you had to make any medical decision since finishing PATH
 - Can you tell me a little about how you came to make the decision
 - Did you use the 'questions to ask when making medical decisions'
- Are there issues you are still uncomfortable/unsure about?
- Would additional visits have been helpful?
 - If so, what topics?

8.B - ONLY TO BE ASKED IF PATIENT IS NOW DECEASED

I'm very sorry to hear that since you completed PATH [X] has passed away. Would you mind telling me if you were able to use what you learned at PATH to help you deal with health care decision before [X] died.

- Did you use the 'questions to ask when making medical decisions'
- Did you encounter any issues you struggled with or were unsure about
 - Would additional visits on this topic have been helpful

9. Thinking about your PATH experience, what about PATH has been most helpful to you?

- The emotional support the physician and nurses provided?
- The information provided to you about [X] health?
- The conversations about future medical care and decisions?
- What could have been more helpful?
 - Barriers: arranging for care during visits, length of visit, other admin issues?

10. If we were going to make changes to this program, what would you recommend we change?

- What should we be sure to keep?

We've talked a lot about your experience with PATH, so now I'd like you to think about how attending PATH has changed things for [X]

- His/her health?
- His/her quality of life?
- His/her attitude about their health
- His/her attitude about dying

11. Is there anything else you'd like to tell me about your experience that I haven't already asked you about?

- Is there anything else related to your role as a substitute decision maker you'd like to share?

Thank you for taking the time to talk with me today. The feedback you provide will not only be used for my thesis project but will be combined with that of other PATH caregivers to ensure we are providing in information, support and care that PATH patients, families and decision makers require.

2010/10/05



Appendix C: Demographic Profile Form



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1. Are you (please circle one):	MALE FEMALE
2. Which age range applies to you? (please check one):	<input type="checkbox"/> less than 30 years old <input type="checkbox"/> 30 to 50 years old <input type="checkbox"/> 51 to 70 years old <input type="checkbox"/> older than 70 years
2. Is your home located in an urban (city) or rural (country) area?	URBAN RURAL
3. What is your occupation?	
4. Has the person you attended the PATH clinic with been diagnosed with a dementia? (for example, Alzheimer's disease, vascular dementia, lewy-body dementia, etc.)	YES NO
5. Did you attend the PATH outpatient clinic or did you meet with the PATH physician in hospital? (please check one)	<input type="checkbox"/> Clinic <input type="checkbox"/> In Hospital
6. What is your relationship with the person you attended the PATH clinic with? (please check one)	<input type="checkbox"/> spouse <input type="checkbox"/> parent <input type="checkbox"/> sibling (e.g., brother or sister) <input type="checkbox"/> other family (e.g., cousin, in-law) <input type="checkbox"/> friend <input type="checkbox"/> other: _____

This study was approved by the Capital District Health Authority Ethics Board
 CDHA-RS/2011-06

2010/10/05