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A STUDY TO INVESTIGATE THE SIGNIFICANCE OF KNOWING ONES'
PROGNOSIS IN PEOPLE DIAGNOSED WITH LIFE-LIMITING ILLNESSES

A Thesis Presented

by

Erika A. Currier, RN

to

The Faculty of the Graduate College

of

The University of Vermont

In Partial Fulfillment of the Requirements
for the Degree of Master of Science
Specializing in Nursing

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ABSTRACT

Background: For patients with life-limiting illnesses, having adequate knowledge of prognosis can strongly impact the choice between curative and supportive treatment.

Objectives: The purpose of this research study is to explore patient understanding of prognosis and to illuminate the experience of having or not having prognostic information in people diagnosed with life-limiting illnesses. This study aims to investigate the patient's understanding of the term "prognosis", the significance of the term "prognosis" to the patient, and how prognosis may or may not affect future treatment choices. In addition, this study aims to further understand the experience of prognostic communication between provider and patient. The over-arching goal is to capture the personal perspectives of participants with a view to exploring their experiences around knowledge of their prognosis.

Methods: A qualitative research design using a phenomenological approach was employed to examine how people experience prognosis. An invitation to participate in the study was publically announced via local newspapers, social media venues, and word of mouth. Participants who responded to study advertisements and who met inclusion criteria were asked to participate in one interview answering open-ended questions aimed at examining their experience with and knowledge of their prognosis. In addition, questions about prognostic communication between patient and health care provider were explored. All interviews were recorded, transcribed verbatim and analyzed using phenomenological methods.

Results: Three study participants met the study criteria and were interviewed. Several themes emerged from the data including 1) patients have need for information about their illness, 2) prognostic data inform treatment choices, 3) patient experiences are unique and 4) patients feel a connection to nurses involved in their care.

Conclusions: This study illuminated the patients' desire and need for information during their illness, the desire for patient autonomy, the difficulty of starting and having prognostic conversations, the downstream impact of having prognostic information, and the important role that nurses play for patients facing serious health issues. It is hopeful that the themes identified during the course of this research ultimately contribute to the knowledge base by informing healthcare providers on the importance of conveying prognostic information in a timely, direct, and sensitive manner.

DEDICATION

This research is dedicated to my dear friend Janet Taplin DeWitt, who succumbed to an aggressive breast cancer on March 26, 2013. Knowing her as I did, I believe her exit from this earth could have been better; more peaceful, more intimate, loose-ends tied up, nothing left unsaid, neat and tidy, as she would have wished. Not that I want to relive the pain of losing her twice, but I wish we could have an end-of-life do-over for her. I would have been stronger for her and I will be stronger for the next person who needs me. Her departure was the inspiration and guiding light for this research.

ACKNOWLEDGEMENTS

I would like to express my deepest gratitude to my thesis advisor, Dr. Judy Cohen, whose expertise, insight, understanding, and patience added considerably to my graduate experience and to this dissertation. I appreciate her vast knowledge and skill in many areas of nursing practice and qualitative research, as well as her willingness to take on this content in light of her own remarkable journey. I also would like to thank the other members of my committee, Dr. Kim Dittus for her insight into the difficult world of a good oncologist, and to Christina Melvin, whose expertise in end-of-life care and end-of-life conversation helped shape this manuscript. Finally, I would like to thank my husband who not only served as my external reader and sounding board, but has been my source of support and strength throughout this career change and graduate study.

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CHAPTER 1

Introduction

For patients with life-limiting illnesses, prognosis can strongly impact the choice between curative and supportive treatment paths. A patient's perception of his or her prognosis is tightly interwoven with how and when the prognosis is conveyed by the health care provider. Knowledge of one's prognosis may significantly alter downstream decisions relating to future medical care, treatment, and preparations for end-of-life care (Silvestri, Pritchard, & Welch, 1998; Huskamp et al., 2009; Temel et al., 2011; Weeks et al., 2012). However, conversations specifically addressing prognostic predictions of disease course are often done poorly, quickly, or omitted between health care providers and patients (Rabow & McPhee, 1999; Christakis & Iwashyna, 1998). Frequently, detailed prognostic conversations are ultimately managed by palliative care specialists late in the course of the disease process.

Prognosis is a prediction of the chance of recovery or survival from a disease (Christakis, 1999; Glare & Sinclair, 2008). In the context of this research, prognostication includes discussions of life expectancy, how the illness may progress, side effects of therapies, potential future symptoms, and functional ability. Most health care providers estimate prognosis based on statistics from the literature of how a disease acts in studies on the general population. Prognoses can vary widely depending on several factors, such as the specific type of disease (i.e., chronic obstructive pulmonary disease, cancer, heart failure, kidney disease, liver disease, etc.), the stage of disease, the progression of the disease, and on the therapies available, attempted or not. Prognoses can also be affected

by the overall health of the individual prior to diagnosis, during treatment, as well as by non-modifiable factors such as genetics, age, race, and gender of the patient (Christakis & Lamont, 2000; Hui et al., 2011; Thomas, O'Leary, & Fried, 2009). Hence, giving an “accurate” prognosis is difficult, complicated, and certainly multifactorial.

Data suggest that prognostic information has value not only to the patient but also to the health care provider and the healthcare system as well (Mack & Smith, 2012; Morrison et al., 2011; Morrison et al., 2008; Penrod et al., 2006; Thompson et al., 2009; Wright, 2008). For the patient, knowing the probable course of his or her disease with or without certain therapies can inform and guide choices to pursue curative, experimental, potentially toxic, surgical, or palliative options. Prognostic data are the cornerstone of informed consent and the basis for autonomous choice by the patient. For patients with life-limiting illnesses, having knowledge of the predicted course of the disease with or without certain therapies is generally how certain therapeutic paths are chosen. For example, if a patient with chronic kidney failure is informed that without a kidney transplant, he has less than 3 months to live but with a kidney transplant, he may live 30 years, he may choose to have surgery. Patients need prognostic information to be fully informed so they can consent (or not) to available therapies.

For the health care provider, having an accurate prognostic outlook allows for conscientious and appropriate use of diagnostic tests, procedures, and treatments and informs risk vs. benefit assessment. For example, if one has a prognosis of less than one month to live, it may not be medically ethical or astute for a provider to order therapies that will likely not change or alter the course of the disease. Likewise, if a patient with a

do not resuscitate (DNR) order has a very low probability of ever being removed from a ventilator once intubated, should the provider choose to intubate at all?

On a larger scale, our healthcare system is widely dependent on prognostic data provided by health care providers as it pertains to health insurance coverage and hospice benefits. For example, without a prognostic assessment from a health care provider of less than 6 months to live, one is unable to receive hospice coverage.

Overview of the Research Problem

The consequences of having inadequate prognostic information at end-of-life are evident at the individual, community, and systems levels. Without prognostic data, patients may not have a realistic view of healthcare options, providers may not be able to justify recommendations or denials of testing and treatment options which may result in a financial burden on our healthcare system pursuing futile therapies. Specific to patients with chronic, life-limiting illnesses, not having access to evolving prognostic data likely limits their ability to receive the full extent of the palliative or supportive comfort care at end-of-life and often leads to late palliation. It is well documented in the literature that the use of palliation and hospice care typically comes late in the course of one's disease which is not ideal for the patient or for the healthcare system. If we can accept that prognostication is a valuable and necessary component to delivering quality healthcare for patients with life-limiting illnesses not only for the patient, but for the healthcare provider and for the healthcare system, the research question becomes: Why is prognostication, especially at end-of-life so challenging?

Purpose of the Study

The purpose of this research study was to explore the patient understanding of prognosis and to illuminate the experience of having or not having prognostic information in people diagnosed with life-limiting illnesses. Through documented conversations with people with serious, life-limiting illnesses, the patient perspective on the timing, the quality, and the importance of having prognostic data was explored to answer the following questions: Do patients understand the term “prognosis”? What is the perspective of patients with life-limiting illnesses on having adequate prognostic data? Do patients feel that they know or that they want to know their prognosis? Are prognostic conversations occurring between health care provider and patient and if so, how often? Do patients have a difficult time accepting or hearing the prognostic information as they struggle with their own mortality or are they eager for more prognostic information?

Conceptual Framework

The theoretical framework chosen to address prognostication and transition to end-of-life is the concept of awareness of dying, first proposed by Glaser and Strauss in 1965. In their book, *Awareness of Dying* (Glaser & Strauss, 2005), the authors introduce the concept that awareness of dying has several stages: suspicion awareness, closed awareness (also called mutual pretense awareness), and open awareness. During an illness, suspicion awareness arises for the patient and family when the patient receives indirect information about failing health via symptoms, conversations, treatments, the internet, and other sources. From that point, the patient and family might move into

mutual pretense (closed awareness) in which all parties agree to behave as if the patient is not seriously or terminally-ill. An open awareness on the other hand is one in which a patient's chronic or terminal status is acknowledged and communicated (although not necessarily accepted) by the patient family and healthcare professional (Nathaniel & Andrews, 2010). Health care professionals face the difficult task of addressing not only the patients' closed awareness of their illness, but their own as well. Both the patient and provider may struggle transitioning to a place of open awareness.

Role of Advanced Practice Registered Nurses (APRN)

An APRN is a registered nurse who has earned a graduate level degree in nursing from an accredited program. The APRN provides competent direct patient care, synthesizes complex assessment data, initiates care plans, prescribes treatments, and uses independent medical and nursing judgment, including the ability to evaluate healthcare environments (American Nursing Association, 2013). APRNs are increasing in presence in both primary and specialty care and significantly more APRNs are expected to join the healthcare workforce in the coming years (Yee, Boukus, Cross, & Divya, 2013). The supply of primary care APRNs is projected to increase by 30 percent, from 55,400 in 2010 to 72,100 in 2020 (U.S. Department of Health and Human Services, Health Resources and Services Administration, National Center for Health Workforce Analysis, 2013). An American Association of Colleges of Nursing (AACN) report from 2012 indicates that there has been a surge in enrollment within graduate nursing programs over the past few years, including accelerated master's programs and in specialty programs focusing on palliative care and critical care advanced practice nursing (End-of-Life

Nursing Education Consortium (ELNEC), *Statewide Effort and Recommendations for the Future Advancing Palliative Nursing Care*, 2012). These increases in enrollment in specialty care nursing education suggest an improved end-of life education and understanding for the graduate level nurse, making her/him a vital member of the end-of-life healthcare team and a leader in providing prognostic data to patients.

Hamric et al.'s Model of Advanced Nursing Practice identifies several core competencies: direct clinical practice, guidance and coaching, consultation, evidence-based practice (EBP), leadership, collaboration, and ethical decision-making (Hamric, Hanson, Tracy, & O'Grady, 2014). These competencies place APRNs in an integral role as part of the end-of-life care team with expertise in prognostication. As experts in coaching and advice, APRNs have the ability to directly affect the emotional and physical welfare patients throughout the course of illness by clarifying goals of care, clarifying treatment options, clarifying prognostic data, facilitating discussions on advanced directives, and managing complex disease processes through end-of-life. APRNs with specific training in end-of-life, critical care, chronic disease management, and in palliative care serve as expert consultants within hospitals and communities both to patients and to peer providers, particularly as it pertains to the delivery and interpretation of prognostic data (Meier & Beresford, 2006). As clinical and professional leaders, APRNs are able to develop educational materials tailored to end-of-life issues, inform policy for both institutions and government, suggest and manage improvements in palliative care programs and monitor healthcare outcomes. As part of the interdisciplinary team consisting of nurses, physicians, social workers, chaplains, and

other caregivers, APRNs collaborate and coordinate to provide the highest quality end-of-life care, which includes relaying prognostic knowledge. To improve quality of care and to inform evidence-based decision making, APRNs utilize current research while also conducting their own investigations. It is clear that advanced practice nurses possess a unique combination of education and skills, making them valuable assets to both patients with life-limiting illnesses and to the institutions that provide end-of-life care.

Significance

Data generated from this research study are intended to inform the future practice of healthcare providers as they co-manage end-of-life care with patients. This study may help to elucidate subtleties of the prognostication process that are currently difficult to assess, such as how patients understand prognosis separate from their diagnosis and how prognostic conversations take place between health care provider and patient. Results from this study could impact future medical and nursing education as it pertains to communication of sensitive health information and end-of-life care. Importantly, a patients' understanding of illness and prognosis has been reported to strongly predict treatment decision-making (Fried, Bradley, Towle, & Allore, 2002; Haidet et al., 1998; Mack et al., 2012) which may have significant downstream consequences for the patient, the health care provider, and the health care system.

CHAPTER 2

Literature Review

A review of the scientific literature reveals several themes surrounding prognostication, or the act of delivering prognostic data to patients. First, prognosticating has changed significantly over time due to increased chronicity of disease, increased treatment options, and increased awareness of a changing paradigm from paternalistic medicine to increased patient autonomy and shared decision-making in medicine. Prognostication is intimately linked to the concepts of maleficence, beneficence, and autonomy, which will be further discussed in detail. A second theme that emerges is that medical education is in part responsible for poor prognostication by health care providers (Rich, 2002). The uncertainty surrounding prognostic data, the lack of attention it has received in modern medical education, as well as a purposeful focus on the practical aspects of medicine has left most health care providers generally ill-equipped to have meaningful, realistic prognostic conversations with their patients (N. A. Christakis & Iwashyna, 1998). Data show that when health care providers do prognosticate, they tend to be overly optimistic when prognosticating at end-of-life, in part due to their unease with delivering what is perceived to be bad news (Christakis & Lamont, 2000). More recently, the lack of prognostic teaching in general medical education curricula as well as an emphasis on symptom control has given rise to specialty providers to fill the void. The prevalence of palliative care teams in United States hospitals showed steady growth between the years 2000 and 2010 and indicates a rapidly rising trend. According to the most recent data, 1,635 or 66% of U.S. hospitals with more than 50 beds have a palliative care team, which is an increase of 148.5% since 2000 (Center to Advance Palliative Care,

2012). Palliative care specialists, as opposed to generalists or primary health care providers, have particular interest, expertise, and training in palliative care and prognostication and are increasingly called on to deliver prognostic information. Thirdly, late referrals to palliative care and hospice care can be directly linked to lack of prognostic data and the unease that health care providers have with prognosticating news of a serious illness (N A Christakis & Lamont, 2000; Lynn, Teno, & Harrell, 1995). Lastly, the majority of patients with life-limiting illnesses prefer to have full disclosure of their disease, including prognostic data (R. G. Hagerty, 2005; Jenkins, Fallowfield, & Saul, 2001)

The Evolution of Modern Prognostication

Prognostication has evolved significantly over time. Fundamental information such as a cancer diagnosis which was withheld in the past is now conveyed to patients as a matter of course. However, wide variations are common in the communication practices of health care providers with respect to other types of health information. Even today, providers hesitate to disclose too much detail related to treatment such as associated risks, side effects of treatment, prognostic information, and potential treatment alternatives (N A Christakis & Lamont, 2000; Lynn et al., 1995).

We can surmise from the quote below, that Hippocrates in 400 B.C. felt no obligation to share diagnostic, treatment or prognostic information with his patients:

“Conceal most things from the patient, while you are attending to him...turn his attention away from what is being done to him...reveal nothing of the patient’s future or present condition” (Jones, 1923, p. 297, 299).

Similar paternalistic sentiments are noted in writings by Dr. Oliver Wendell Holmes Sr., a Harvard trained, respected physician, medical professor, and medical reformist as he taught his medical students:

“Your patient has no more right to all the truth you know than he has to all the medicines in your saddlebags...he should only get as much as is good for him” (Holmes, 1891, p. 388)

Prognostication and Autonomy

It is difficult to talk about the evolution of prognostication without talking about the evolution of patient autonomy in healthcare. Autonomy is most often described as the right of each individual to self-determination or self-rule (Beauchamp, 2009; Johnson, 2006). Opposite of autonomy is paternalism, “when a health care provider decides what is best for the patient and carries out interventions with minimal consent” (Johnson, 2006, p. 78). Over the past 75 years, there has been a paradigm shift away from paternalism and toward patient autonomy. Medical autonomy then refers to healthcare decisions and interventions the patient will or will not receive as ultimately being the patient’s decision (Entwistle, Carter, Cribb, & McCaffery, 2010).

The principle of autonomy includes certain criteria that must be fulfilled or understood to ensure true autonomy: The individual must be competent and aware of the medical issue at hand. The patient must be aware of the options surrounding the decisions to be made. The individual must be well-informed of the pros and cons for all of the available treatments and the individual’s decisions must be free from persuasion, coercion, and manipulation (Beauchamp, 2009; Johnson, 2006). Arguments in favor of

patient autonomy include giving the patient a sense of control over their health and the care the patient receives, as well as considering the uniqueness of each patient's individual situation to ensure the decision made is in fact the best option for that particular patient (Entwistle et al., 2010). Autonomy advocates for a reduction in paternalism and in the "provider knows best" mentality by moving the patient's wishes to the forefront. It follows then that truly autonomous decisions are informed decisions and to be truly informed, the patient must be knowledgeable of not only his/her diagnosis, but also his/her treatment options, potential side effects of therapies, and prognosis with and without interventions.

Indeed, prognostic data is the cornerstone of informed consent. For terminally ill patients, understanding an incurable prognosis is viewed as beneficial and allows for informed healthcare decisions (Daugherty & Hlubocky, 2008). In fact, true informed consent, must comprise a thorough appraisal of the clinical situation (diagnosis, comorbidities, pathology), clearly outline the various treatment options based on the clinical situation, and outline the prognosis given the proposed treatment options (Glare & Sinclair, 2008). It is well established that patients facing a life limiting illness, may not comprehend their prognosis and often over estimate their time to live or the benefit of the treatment they are receiving (SUPPORT Study, 1995). As part of the Study to Understand Prognoses and Preference for Outcomes and Risk of Treatments (SUPPORT) trial, which was a prospective cohort study conducted at five teaching hospitals in the United States between 1989 and 1994, 512 patients with newly diagnosed metastatic colorectal cancer, along with their health care providers, were asked to estimate the

likelihood of surviving their disease 2 months and 6 months. Patients had high estimates of 2- and 6-month survival as compared to their health care providers. More than 4 in 5 patients estimated that their likelihood of being alive in 2 months was 90% or more whereas the median physician estimate of 2-month survival was 80%. Three quarters of the patients estimated that their likelihood of 6-month survival was at least 90%, whereas the median physician estimate of 6-month survival was 50%. Overall actual survival for the cohort was 78% at 2 months and 56% at 6 months (SUPPORT Study, 1995).

Another study suggests that many patients with terminal lung cancer did not recall being offered any alternatives to chemotherapy, and that many would not have taken chemotherapy based on the actual survival benefit (Silvestri et al., 1998). Several studies have shown that patients with metastatic cancer and their families often fail to comprehend the goals of therapy, maintaining inaccurate illness perceptions and expectations about the purpose of treatment (Temel et al., 2011; Huskamp et al., 2009). For example, in a recent large, national, prospective cohort study, the majority of patients (69% with metastatic lung and 81% with metastatic colorectal cancers) failed to understand that chemotherapy was not at all likely to cure their cancer (Weeks et al., 2012). In the metastatic setting, chemotherapy may offer palliation and some prolongation of life, so it represents a reasonable treatment choice for some patients. However, an argument can be made that patients with metastatic disease who do not have a sustained understanding that chemotherapy cannot cure their cancer have not met the standard for true ongoing informed consent to their treatment. The implication is clear: when patients do not fully understand their prognosis, they can be considered largely

uninformed in their treatment options, potentially leading them down unintended treatment paths.

Prognostication, Maleficence, and Beneficence

For centuries, health care providers have been guided by the ethical principles of non-maleficence and beneficence: do no harm, and do good, respectively (Beauchamp, 2009). These concepts were much clearer and less complicated at the time of Hippocrates as the availability of medical interventions was limited. In Hippocrates era, disease was diagnosed later, was less chronic, had few interventions, and often resulted in a relatively sudden death. Today however, there are a host of medical interventions and choices that have the potential to change the course of disease and could potentially do harm or good for the patient. The chronicity of modern disease has significantly increased with time and with the availability of new treatment options resulting in patients living longer. The potential for harm from medical intervention makes considering non-maleficence and beneficence more thought provoking and difficult as “there is no longer a duty just to do whatever we can; rather, we need to ask whether we *should* do what we can do, when there is a real chance of making the patient worse” (Johnson, 2006, p.90). It is exquisitely evident how prognostic predictions and maleficence and beneficence are linked at end-of-life. Questions often encountered by both patients and healthcare providers at the end-of-life such as “Will the proposed intervention help the patient or might it hurt the patient?” “Will palliative measures reduce pain and harm, or potentially hasten death?” “Does the benefit of doing “x”

outweigh the risk of not doing “x”?” “Or does the benefit of “doing x” outweigh the benefit of “doing y”?”

When considering health care options at end-of-life, the debate between non-maleficence and beneficence becomes whether or not death is perceived as harmful to the patient (Beauchamp, 2009). To assess this, the risks and benefits of all options, including both symptom management and disease treatment must be reviewed with the patient to ensure the maximization of life within the means of trying to not to do harm and to do good. The risk vs. benefit analysis is fluid and intimately intertwined with the patients’ values and the prognostic information available at any given time (Beauchamp, 2009).

Barriers to Prognostication

Medical Education

Textbooks of internal medicine typically divide their discussion of diseases into four sections: etiology, clinical presentation, diagnosis, and treatment. Texts infrequently consider prognosis explicitly and even less frequently do they devote special sections to prognosis. Medical education has historically been heavily focused on the physical exam, concentrating on creating a diagnosis based on physical exam findings, and formulating a treatment plan to best treat the disease (Maida & Cheon, 2014). The physical exam is how data are collected to piece together the likely diagnosis. The actual diagnosis is the explicatory piece, rooted in disease etiology and pathophysiology. The treatment plan is the managerial piece of medicine, or how one plans to reverse or slow the patient’s disease.

Prognosis, or the prediction of the probable course of a disease, is less studied and often given little focus in medical education (Maida & Cheon, 2014). Historically, much of the focus in medical training has been on diagnoses and treatment, with far less emphasis on the importance of an accurate prognosis (Maida & Cheon, 2014; Rich, 2002). In a survey of 697 physicians assessing attitude and self-reported comfort levels prognosticating to terminally ill patients, 57% reported inadequate training in prognostication techniques, whereas only seven percent believed their diagnostic training was inadequate; with regard to prescribing therapies, only six percent felt under-prepared (Christakis & Iwashyna, 1998).

Contemporary textbooks of internal medicine give scant attention to the prognosis of diseases, and as such, prognosis is widely understudied (Nicholas A. Christakis, 1997; Maida & Cheon, 2014). Christakis (1997) reviewed the highly regarded, standard medical textbook initially authored by William Osler, *The Principles and Practice of Medicine*, performing qualitative and quantitative content analysis of entries regarding lobar pneumonia in selected editions published between 1892 and 1988, with special attention to the period between 1892 and 1947. What he found was that the proportion of chapter length devoted to seven clinical tasks (Etiology, Presentation, Pathology, Diagnosis, Therapy, Prognosis, and Complications) changed significantly over time. In the 1892 version of the text, the majority of the chapter on lobular pneumonia was dedicated to the presentation of the disease, while the other six categories roughly have equal coverage in the text. Specifically, in the 1892 edition of the text, the material on prognosis is about as long as that on diagnosis and therapy. Contrast this to the 1988

version of the text, where the majority of the chapter on lobular pneumonia was devoted to the diagnosis of the disease and there is no explicit discussion of prognosis at all (Christakis, 1997). The 1947 edition of the text is intermediate between the 1892 version and the 1988 version, showing an increase in attention to available therapies and a decrease in material relating to prognosis (Christakis, 1997).

Prognostic Accuracy

With a significant increase in chronic illness in the United States, prognostic accuracy is more complex than ever before. One hundred and fifty years ago, death from disease typically came earlier and was often expected by both the patient and the health care provider. Today, prognostic accuracy is influenced by many factors such as increased life expectancies, earlier diagnoses, novel and experimental treatments for many chronic conditions such as cancer, heart disease, COPD, and diabetes, as well as conditions that were once fatal that are now treatable but not necessarily curable. Several studies in the literature point to poor prognostic ability of health care providers (Christakis & Lamont, 2000; Thomas, O'Leary, & Fried, 2009; Hui et al., 2011), which is obviously complicated by the complexity and variability of disease.

In a prospective cohort study of 468 patients entering hospice care, physicians were asked to estimate time to death for each admitted patient. When an accurate prediction was defined as between 0.67 and 1.33 times the actual survival, ~20% (92/468) of predictions were accurate, with ~63% (295/468) optimistic, and ~17% (81/468) pessimistic. When an accurate prediction was defined as between 0.50 and 2.0 times the actual survival, ~34% (159/468) of predictions were accurate, with ~55%

(256/468) optimistic, and ~11% (53/468) pessimistic. Death occurred within one month of the predicted date for 42% (195/468) of patients, at least one month before the predicted date in 46% (214/468), and at least one month after the predicted date in 13% (59/468) of patients (Christakis & Lamont, 2000). In this study, diagnoses affected accuracy. Predictions of survival by oncologists for patients with cancer diagnoses were more accurate than cardiopulmonologists predicting survival of patients with COPD. There was no influence on prognostic accuracy related to the physician's age, gender, years in practice, or self-described optimism. In all medical subspecialties, the error in prognostic accuracy was systematically optimistic such that the average time to death was predicted to be longer than the actual time to death. Likewise, as the duration of the doctor-patient relationship increased and time since last contact decreased, prognostic accuracy decreased (Christakis & Lamont, 2000).

In a similar study where physicians and nurses were asked to predict time to death for patients with advanced cancer, again both physicians and nurses systematically overestimated survival times, with nurses being more optimistic about survival times than physicians (Hui et al., 2011). In the same vein, a majority of oncologists state that they typically provide accurate prognostic information to patients with terminal cancer, although data point to the contrary and suggests that clinicians routinely communicate overly optimistic survival estimates to patients (Christakis & Lamont, 2000; Thomas et al., 2009). In another study investigating hospice conversations between providers and patients with life-limiting illnesses such as cancer, COPD, and heart failure, over the course of the study, a total of 56% of the participants died, which included patients with

cancer (77%), patients with COPD (42%), and patients with heart failure (47%). A sizeable portion of these patients (~40%) had clinicians who provided a life expectancy estimate of >1 year, within six months prior to patient death (Thomas et al., 2009).

Prognostic accuracy has improved with the migration away from a temporal framework toward a probabilistic prognostic method. To demonstrate the difference, the temporal approach might pose the question: “What is the approximate duration of survival for this patient?” The probabilistic approach most often used today asks a similar question but in a different way: “What is the approximate probability that this patient will be alive (0-100%) after some time period?” Hui et al., 2011 looked at clinical prediction of survival (CPS) in 151 patients with advanced cancer and showed that the temporal approach to predicting time to death was much less accurate than the probabilistic approach for both doctors and nurses. Comparing physicians and nurses, it was found that nurses were significantly more accurate in their prediction of survival at 24 hours (91% versus 71%) and at 48 hours (86% versus 66%). In contrast, physicians were significantly more likely than nurses to provide accurate prognostication for the 6-month time point (96% versus 88%) (Hui et al., 2011).

Christakis writes in his book *Death Foretold*, “Despite its usefulness, physicians regard prognosis with anxiety and disdain, and they avoid it if possible. If patients do not insist on being told, physicians generally will forswear making a prediction or will be as vague as the situation permits” (Christakis, 1999, p. 84).

Prognostication is not fun, easy, or rewarding

Many health care providers feel uncomfortable prognosticating at the end-of-life, and they avoid doing so. The reasons providers cite for not prognosticating well are many: they feel uncomfortable with the unpredictability of disease from patient to patient, they feel medically under-trained in prognostication, they feel stress and anxiety when having to prognosticate, and they wish to stay optimistic for their patients (Christakis & Iwashyna, 1998; Daugherty & Hlubocky, 2008). No doubt, delivering a poor prognosis to a patient or to a patient's family is an unpleasant task. Health care providers do not wish to take hope away from the patient. They may be fearful of the patient's or family's reaction to the news, or uncertain how to deal with an intense emotional response. In addition, poor prognostic information often must be delivered in settings that are not conducive to such intimate conversations and the hectic pace of clinical practice may force a health care provider to deliver bad news with little forewarning or when other responsibilities are competing for time and attention. Health care providers may feel that they have failed the patient. The cumulative effect of these factors is provider uncertainty and discomfort with prognostication and a resultant tendency to disengage from situations in which they are called on to break bad news. Rabow and McPhee (1999) keenly describe the end result, "Clinicians focus often on relieving patients' bodily pain, less often on their emotional distress, and seldom on their suffering" (Rabow & McPhee, 1999, p.260).

Making predictions for the future can be stressful, especially in the setting of a terminal illness. One study showed that 91% of health care providers found prognostication to be exceedingly more difficult than providing a diagnosis to a patient

(Christakis & Iwashyna, 1998). Providers tend to feel quite comfortable analyzing the facts gathered to generate the “History of the Present Illness.” They are much less comfortable predicting the “Future of the Present Illness”, especially when coupled with an unfavorable prognosis (Christakis & Iwashyna, 1998). Whereas diagnosis is hinged on facts and data, prognosis is much more unpredictable and uncertain. In addition, one’s prognosis may be altered by the course of treatment chosen.

Prognostication is especially stressful and taxing to health care providers who have a long-standing relationship and on-going responsibility for their patients’ care. Many specialists report that they are often left to be the bearers of bad news, as the generalist with a long-standing relationship with the patient tends to paint an over-optimistic picture (Gawunde, 2010; Anspach, 1997). Generalists on the other hand, often feel that it is their duty to “soften the blow” by staying optimistic and offering a compassionate view in light of the often crushing bluntness of a specialist delivering a poor prognosis (Anspach, 1997).

Reasons for the stressfulness of prognostication identified by Christakis and Iwashyna (1998) included feelings that patients want too much certainty and accuracy from the prediction. In addition to the perception of a high standard, providers feared being judged by patients and other clinicians if their prognosis was wrong (although they were more worried about getting the diagnosis wrong). Providers were found to avoid prognosticating, generally waiting to be asked rather than volunteering a prediction. Doctors described more reluctance to prognosticate when the clinical situation was atypical and the course seemed more uncertain than usual (Christakis & Iwashyna, 1998).

A repeatedly cited barrier to prognostication at end-of-life is the concern that such conversations may cause patients to feel distress or lose hope. However, depression and worry are not reported to be higher in patients who report having end-of-life discussions with their health care providers (Mack & Smith, 2012; Wright, 2008). In fact, patients with advanced cancer who are aware and express acceptance of their prognosis are less likely to feel depressed, anxious, or hopeless (Thompson et al., 2009). Importantly, studies show that patients who recalled discussing plans for end-of-life care received less aggressive care near death and were more likely to have an earlier referral to hospice and to experience a better quality of death (Wright, 2008; Mack et al., 2012).

Consequences of not Prognosticating

The result of not having prognostic conversations in the terminally ill population may contribute to a delay in hospice and palliative care (Borowske, 2012; Bradley et al., 2001; Wright, 2008; Mack & Smith, 2012), may perpetuate futile treatments (Huynh et al., 2013), may result in increased healthcare system burden and cost (Endacott, 2012; Huynh et al., 2013), and ultimately contribute to patient under preparedness for end-of-life and unnecessary patient suffering (Bradley et al., 2001; Temel, Greer, Admane, et al., 2010).

Delay in Palliative and Hospice Care

Prognostic confusion may play a role in late referrals and under-utilization of hospice care. Many terminally ill patients enroll in hospice only in the final days before death or not at all. Discussing prognosis and the options for palliative and hospice care with a health care provider could increase awareness of palliative options and possibly

result in earlier use (Huskamp et al., 2009; Wright, 2008; Mack & Smith, 2012). In a study of 1,517 patients diagnosed with stage IV lung cancers who were interviewed between 4 and 7 months after initial diagnosis, only 53% recall discussing hospice care options with their health care provider (Huskamp et al., 2009). As median survival after diagnosis for patients with stage IV lung cancer is approximately 4 to 8 months (Kato, Severson, & Schwartz, 2001; Bradley et al., 2001; Earle et al., 2000), a discussion with a provider about hospice within 4 to 7 months after diagnosis was appropriate for these patients. Interestingly in this study of individuals who died within 2 months after the interview, only 53% had discussed hospice with their health care provider, and rates were lower among those who lived longer (eg, 33% of patients who died between 2 and 4 months after the interview and 21% of patients who died more than 8 months after the interview). Patients who discussed hospice with a provider were more likely to enroll in hospice. Seventy percent of patients who had a discussion before the study interview used hospice services within a year of diagnosis compared with 26% of those who did not. Patients who reported that they expected to live less than 2 years had much higher rates of hospice discussion than those expecting to live longer. Patients reporting the most severe pain or dyspnea were no more likely to have discussed hospice than those reporting less severe or no symptoms. Most importantly, more than three-quarters of patients who reported a preference for relieving pain over extending life had not discussed hospice with their health care provider. A third of patients who reported discussing do-not-resuscitate preferences with their provider had also discussed hospice (Huskamp et al., 2009).

In another study, a disconnect in communication of prognostic information between patients and clinicians was shown to impede treatment decision-making and lead to a delay in referrals to palliative or hospice care (Detmar, Aaronson, Wever, Muller, & Schornagel, 2000). Detmar et al. (2000) showed that although both patients and oncologists were willing to discuss a wide range of health related quality of life issues, communication regarding psychosocial issues, such as mortality was hampered by competing expectations as to who should take the lead in initiating such discussions. In a study (Mack et al., 2012) examining communication of psychosocial issues at end-of-life, providers interviewed indicated that they generally defer to their patients in initiating discussion of psychosocial issues. Several groups have also shown that many end-of-life discussions occur late in the course of illness, leading to hospice referrals that occur within days of death (Mack et al., 2012; Christakis & Escarce, 1996). Mack et al. (2012) showed that most end-of-life conversations begin in the final weeks of life, long after decisions about treatments are likely to have taken place. In a study of 2,155 patients with stage IV colorectal or lung cancer, 55% of first end-of-life discussions documented in records occurred in the hospital. Oncologists documented end-of-life discussions with only 27% of their patients. Among patients with documented end-of-life discussions who died during follow-up, discussions took place on average 33 days before death. Few patients had documented conversations about palliative care, even though early palliation offers important benefits to patients with incurable lung cancer throughout the disease trajectory (Temel, Greer, Muzikansky, et al., 2010), including better quality of life and longer survival. Conversations about end-of-life care may therefore best take place near

the time patients are diagnosed with advanced cancer, rather than in the last weeks or days of life.

Patients who have less time to live than they believe are likely not getting the fullest extent of palliative care possible (Borowske, 2012; Huynh et al., 2013). Despite the high satisfaction reported by descendants of hospice enrollees (Price et al., 2014), 35% of all hospice patients die within seven days of enrollment owing to late referrals (Borowske, 2012). In a recent survey of hospice care satisfaction (Price et al., 2014), the average overall rating of care by the more than 1,100 individuals who reported on the experiences of hospice decedents in the survey was 93 out of 100. Average scores for each composite were generally high, ranging from 81.0 for Understanding the Side Effects of Pain Medication and 85.2 for Hospice Care Training to 94.9 for Information Continuity and 95.7 for Treating Your Family Member with Respect. Chain hospices tended to have lower adjusted mean scores than non-chain hospices (Price et al., 2014).

With the early involvement of palliative care, patients with advanced cancer and their families have the opportunity to develop a long-standing relationship with members of the palliative care team (Temel et al., 2007). Developing this therapeutic alliance helps to build trust that facilitates difficult conversations regarding prognosis as well as the process of weighing the risks and benefits of different treatment options in the context of the patient's and family's goals for care. Moreover, palliative care clinicians are able to support the health care team's effort to communicate accurate information about prognosis, especially since achieving such an understanding often requires multiple conversations and an evolution in awareness and emotional acceptance. That is, the

delivery of prognostic information is more of a process than a single event, with consideration of patients' preferences for the amount and timing of information they desire (Back, Arnold, Baile, Tulsky, & Fryer-Edwards, 2005; Back & Arnold, 2006a; Back & Arnold, 2006b). In addition, in a co-management model, palliative care teams have the role and credibility to assist patients and their families to manage symptoms, discuss goals of care, and make informed treatment decisions. Nonetheless, this role is distinct from that of the health care provider, who patients expect to focus on directing cancer therapy, stabilizing disease, and prolonging life. At times, patients and their families may filter their concerns regarding symptoms, disease burden, and an uncertain future for fear that the health care provider may abandon or “give up” on them (Back et al., 2009). The parallel clinical relationship with palliative care, whose primary focus is on enhancing quality of life through improved symptom management and psychosocial support, provides a natural opportunity for patients and their families to clarify questions about prognosis and discuss openly their concerns, symptom burden, fears, and treatment wishes (Greer, Jackson, Meier, & Temel, 2013).

Futile Treatments

Several studies have shown that cancer patients with metastatic disease tend to over-estimate the length of time they have left to live, even as their health care providers have a more accurate prognosis, which also may lead to futile therapies (Lux et al., 2013; Mende et al., 2013). Patients are generally willing to undergo treatments that have small benefits with major toxicity. Receiving realistic information about the different options of care and the likelihood of successful treatment or adverse effects is difficult and may

explain some of the increased use of chemotherapy near the end-of-life (Matsuyama, Reddy, & Smith, 2006). Further research is needed in regards to why patients with very limited life expectancy continue to pursue curative therapies.

In a large study (Lux et al., 2013) polling 9,000 patients diagnosed with breast cancer (any stage) and 6,938 physicians about the perceived efficacy of various treatments for metastatic breast cancer, it was found that patients expected much greater benefits from the therapies offered than the health care provider. For all treatment modalities (chemotherapy, endocrine therapy, antibody therapy, radiotherapy, and bisphosphonates), about 50 % or more of patients expected more than a 12-month increase in overall survival from all therapies. Among the doctors, this proportion ranged from 7 to 30%. The response rate was 23.9% (2155) for patients and 7.6% (527) for physicians (Lux et al., 2013).

In a study of 134 patients with metastatic disease who had already received a median of 6-months of chemotherapy, Mende et al. (2013) found that 88% stated they would undergo treatment again. However, when asked to specify the minimum survival gain necessary for them to repeat therapy, study participants' median thresholds for survival were 18 months for non-colorectal cancer patients and 36 months for colorectal cancer patients. So while the majority of patients in this study would repeat chemotherapy, this was based on expected benefits that *far* exceed the actual survival gains offered by anticancer agents in the metastatic disease setting (Mende et al., 2013). In the colorectal cancer group, the median expected survival was 44.0 months compared with a median actual survival of 30.0 months. For non-colorectal cancer patients the

median expected survival was 22.0 months compared with a median actual survival of 19.0 months. In both cohorts, the expected survival was significantly longer than the actual survival (Mende et al., 2013).

Avoidance of conversations regarding prognosis and care preferences between health care providers and their patients also limits discussion and documentation of patients' goals as articulated in advance directives (Bradley et al., 2001). Discussion of prognosis was recorded for 89 of 232 (38%) patients with brain, pancreas, liver, gall bladder, or inoperable lung cancer. Of those patients who had a discussion recorded, 46 (52%) had only one such discussion recorded with their health care provider during the course of their illness. Documentation of discussions about prognosis included a specific time frame for life expectancy for only 8 (9%) patients. Additional content of documented discussions about prognosis included plans for future treatment or care for 40 (45%) patients, specific patient or family treatment preferences for 25 (28%) patients, and general information and additional support for 26 (29%) patients (Bradley et al., 2001).

Importantly, patients' understanding of their illness and prognosis is reported to strongly predict treatment decision-making (Fried et al., 2002; Cosgriff, Pisani, Bradley, O'Leary, & Fried, 2007; Haidet et al., 1998). While patients with advanced cancer who view themselves as terminally ill are more likely to prefer and receive symptom-directed care at the end-of-life, those who overestimate their prognosis are more likely to receive cancer-focused therapy of unclear benefit during the last month of life (Mack, Weeks, Wright, Block, & Prigerson, 2010; Weeks et al., 2012). Mack et al. (2010) assessed end-of-life preferences in patients with terminal cancer at a median of 125 days before death.

Overall, 68% of patients (220 of 325 patients) received end-of-life care consistent with their baseline preferences. The proportion was slightly higher among patients who recognized they were terminally ill (74%, 90 of 121 patients). Patients who recognized their terminal illness were more likely to prefer symptom-directed care (83%, 100 of 121 patients; vs. 66%, 127 of 191 patients). However, some patients who were aware they were terminally ill wished to receive life-extending care (17%, 21 of 121 patients). Patients who reported having discussed their wishes for end-of-life care with a physician (39%, 125 of 322 patients) were more likely to receive care that was consistent with their preferences, both in the full sample and among patients who were aware they were terminally ill. Among patients who received no life-extending measures, physical distress was lower (mean score, 3.1 v 4.1) among patients for whom such care was consistent with preferences (Mack et al., 2010).

The Weeks et al. (2012) study sought to characterize the prevalence of the expectation that chemotherapy might be curative for metastatic colorectal and lung cancer and to identify the clinical, social, demographic, and health-system factors associated with this expectation. Of 1,274 patients with stage IV lung or colorectal cancer who were alive at the time of the baseline survey (4 months after diagnosis) and who discussed chemotherapy with at least one physician, 1,193 (93.6%) opted to receive chemotherapy. Patients then reported expectations about the effectiveness of chemotherapy for the outcomes of cure, life extension, and symptom relief. Overall, 69% of patients with lung cancer and 81% of those with colorectal cancer did not report understanding that chemotherapy was not at all likely to cure their cancer. Paradoxically,

patients who reported higher scores for provider communication were also at higher risk for inaccurate expectations (Weeks et al., 2012).

Under preparedness for End-of-life

The continued pursuit for treatment, combined with a failure to recognize the dying process, can rob patients of a peaceful, dignified death as well as meaningful time left free of time-consuming treatments and side effects of treatment. The initiation of early end-of-life planning and palliative care is limited by the existing paradigm of death as an 'enemy to be defeated'. Early discussions about end-of-life care may help patients with the psychological work of the end-of-life period, including acceptance of one's life situation, grief over the losses inherent in death, and growth in relationships (Mack et al., 2012).

As previously described, prognostic communication between patient and provider is often lacking, as are clear communication of end-of-life wishes. With a late change in focus from curative treatments to palliative treatments, patients often feel unprepared for end-of-life. In a retrospective study of 2,498 patients at an academic medical center with metastatic solid tumors, only 20% of patients had resuscitation preferences documented in their electronic medical record (Temel, Greer, Admane, et al., 2010).

In a survey given to palliative care professionals to assess barriers to early palliative care, Feeg (2005) found that the top three barriers to early palliative care or hospice were 1) physician reluctance to make referrals, 2) physician lack of familiarity with availability and suitability of hospice, and 3) association of hospice with death. Similarly, Melvin (2010) and Melvin & Oldham (2009) found that the greatest

contributing factor to late referrals by health care providers to palliative care or hospice was lack of knowledge about palliative care services offered. Barriers connected to physician initiation of hospice or palliative care presume that the physician-patient conversation is a necessary first step in seeking alternative care approaches and, therefore, relies on the philosophical approach of the physician, whose mission “to heal” complicates reconsideration of options (Feeg, 2005).

Poignantly, Atul Gawande, a Boston surgeon and public health researcher writes “...the way we deal with death today is that we have forgotten the art of dying. All-out treatment, we tell the terminally ill, is a train you can get off at any time—just say when. But for most patients and their families this is asking too much. They remain driven by doubt and fear and desperation; some are deluded by a fantasy of what medical science can achieve” (Gawande, 2010, p. 24).

Cost

Lack of accuracy in predicting time to death in the terminally ill population may contribute to increased health care cost. Terminally ill cancer patients who believe they have more than six months to live are 2.6 times as likely choose curative, often aggressive and expensive therapy over palliative therapy and are willing to suffer significant adverse side effects of treatment (Matsuyama et al., 2006).

Reimbursement for end-of-life care is complex and has been inadequate to date. Truthfully, the impact of reimbursement on practice patterns has not been fully studied. Health care providers are more likely to be reimbursed for ordering chemotherapy than they are for engaging in long conversations with patients and their families about end-of-

life concerns. For example, there are current procedural terminology codes for “Family Conference” listed under Center for Medicare and Medicaid Service forms, but the actual reimbursement is \$0. As recently as 2001, more than 50% of the profit in private practice came from the sale of the chemotherapy drugs, supporting much higher salaries than would be possible with evaluation and management coding (Smith, Girtman, & Riggins, 2001). However, with the passage of the Medicare Modernization Act (MMA) in 2003, the reimbursement structure for chemotherapy drugs was altered to limit excessive profits from the sale of chemotherapy to a 6% administration fee (*Medicare Prescription Drug, Improvement, and Modernization Act of 2003*, 2003). Still, health care providers can make more money prescribing chemotherapy than consulting with patients on their illness. The impact of alternative reimbursement methods will be an active area of investigation during the next several years.

There are also financial consequences of patient willingness to do almost anything for a small benefit. Late referrals to hospice will bankrupt hospices that receive \$100 a day for all care. The rapidly escalating cost of chemotherapy, up to \$30,000 for a 6-month course of new pharmaceuticals and monoclonal antibodies, will add new cost to an already strained health care finance system. Cost-saving hospital-based palliative care (Smith et al., 2003; Elsayem et al., 2004) and cost neutral hospice care (Campbell, Lynn, Louis, & Shugarman, 2004) cannot offset these high costs.

Data from 1996 showed that 22% of all Medicare patients started a new chemotherapy regimen in the last month of life. Likewise, treatment within two weeks of death has increased from 13.8% in 1993 to 18.5% in 1996. A 2005 study showed that

chemotherapy was administered to 34% of patients in their last 2 weeks of life. During this same period, the cost of colon cancer chemotherapy increased from \$500/course to more than \$30,000/course (Matsuyama et al., 2006). The implications of using expensive treatments with little benefit are clear: Late referrals to hospice have the potential to bankrupt hospice programs that receive as little as \$100/day for all palliative care services. Cost saving palliative care, whether home based or hospital based, cannot overcome the cost of expensive, “last ditch” chemotherapy efforts at end-of-life.

Accumulating evidence suggests that palliative care consultation programs are associated with significant hospital cost savings (Morrison et al., 2008; Morrison et al., 2011; Penrod et al., 2006). Although data are lacking with respect to the health care expenditures for the early integration of palliative care into standard oncology care, the co-management model has the potential to improve resource use by addressing patients’ symptoms immediately and collaboratively as they emerge, ideally reducing the likelihood of excessive procedures, emergency department visits, and acute hospital stays. For example, Brumley et al. (2007) observed fewer emergency department visits and hospital admissions, as well as lower costs of care, with use of an in-home palliative care intervention (Brumley et al., 2007). At a minimum, early palliative care appears to assist patients and families with making difficult decisions about treatment at the end-of-life, minimizing the potentially harmful effects and high costs of near-death chemotherapy while maximizing quality of life (Greer et al., 2013).

Patients want prognostic information

Studies show that patients with advanced cancer and their families report a desire to receive timely and realistic prognostic information (Jenkins, Fallowfield, & Saul, 2001; Hagerty et al., 2005; Hagerty et al., 2004; Steinhauser, Christakis, et al., 2000; Steinhauser, Clipp, et al., 2000). Greater than 95% of individuals with cancer want their physician to be realistic and believe that they should be told if their illness is terminal, with the majority endorsing that the information should be communicated immediately after diagnosis (Hagerty et al., 2004; Yun et al., 2004). However, as previously discussed, patients with metastatic cancer and their families often fail to comprehend the goals of therapy, maintaining inaccurate illness perceptions and expectations about the purpose of treatment (Temel et al., 2011; Huskamp et al., 2009).

Jenkins et al. (2001) showed that 87% of patients receiving cancer treatment preferred to have as much information as possible, both good and bad. One hundred twenty five (5.4%) preferred to have additional information only if it was good news and 179 (7.7%) preferred to leave it up to the doctor. Of the 2,331 patients who participated in the study, 940 (40%) were receiving curative treatment, 841 (36%) palliative treatment, 215 (9%) were in remission and for 335 (14%) treatment intent was still uncertain (Jenkins et al., 2001). The results from this large survey support previous research that most patients want as much information as possible about treatments and illness. Furthermore 95% wished to know what their chances of cure were, hence information about prognosis should not be avoided (Jenkins et al., 2001).

Hagerty et al. (2004) showed similar results in a study of 126 patients with metastatic cancer. More than 95% of patients wanted information about side effects, symptoms, and treatment options. The majority of study participants (85%) wanted to know longest survival time with treatment, 80% wanted to know 5-year survival rates, and 81% wanted to know average survival. Words and numbers were preferred over pie charts or graphs. Fifty-nine percent wanted to discuss expected survival when first diagnosed with metastatic disease. Thirty-eight percent and 44% wanted to negotiate when expected survival and dying, respectively, were discussed (Rebecca G. Hagerty et al., 2004).

Steinhauser et al. (2000) showed in a large study that what is important for patients at end-of-life included pain and symptom management, communication with one's physician, preparation for death, and the opportunity to achieve a sense of completion are important to most in having a "good death". Clearly, being aware that death is approaching is key to preparing for end-of-life and requires knowledge and acceptance of honest prognostic information (Steinhauser, Christakis, et al., 2000).

As discussed above, the literature overwhelmingly suggests that the repercussions of not having prognostic conversations dynamically throughout the disease process lead to late referral to palliative support, trials of futile curative treatments, increased health care costs, uninformed patient decision making, and under preparedness for end-of-life. The research study presented here is significant in that it explored the patient perspective of receiving and processing prognostic information from the health care provider.

CHAPTER 3

Research Questions

The purpose of this research study was to explore the patient understanding of prognosis and to illuminate the experience of having or not having prognostic information in people diagnosed with life-limiting illnesses. This study aimed to investigate the patient's understanding of the term "prognosis", the significance of the term "prognosis" to the patient, and how prognosis may or may not affect future treatment choices for the patient. In addition, this study aimed to further understand the experience of prognostic communication between provider and patient.

Methodology

A qualitative research design using a phenomenological method was utilized to explore the research questions for this study. This phenomenological method was chosen to explore the unique lived patient experience without influence from previous research. Interview questions were designed to elucidate the essence of the patients' experience around prognostic information as they navigated through a serious medical illness. The patient experiences were then interpreted and compared to the known phenomenon found in the literature.

This research study employed purposive sampling and interviews comprised of open-ended questions relating to the area of interest (Appendix A). The open-ended questions were specifically designed to extract the participants experience around the phenomena being studied, without influencing or biasing the participant's response. Open-ended questions are often used in exploratory research and are appropriate for this

type of phenomenological, qualitative research. The intention of the interview was to capture the personal perspectives of participants with a view to exploring their experiences within the context of the area under investigation (Ritchie & Lewis, 2003), and in this study, the experiences around knowledge of prognosis.

An interpretive, iterative approach (also called Heideggerian hermeneutics (Polit, 2012)) was used to analyze the data and is signified by the Hermeneutic circle. The circle signifies the methodological process in which to reach understanding of the data, there is continual movement between the parts and the whole of the text being analyzed (Polit, 2012). In addition, the circle signifies a methodological process of understanding where in order to understand the meaning of the whole experience, an understanding of the individual parts of each experience must be analyzed as an interdependent activity to circle back and inform the whole. Constructing meaning from the whole means making sense of the parts, and grasping the meaning of the parts depends on having some sense of the whole (*The SAGE Dictionary of Qualitative Inquiry*, 2007).

The quality of the qualitative research proposed will be assessed by evaluation of the credibility, transferability, dependability, and confirmability of the data and emphasizes striving for truth through the qualitative research process (Nigatu, 2009)(*The SAGE Dictionary of Qualitative Inquiry*, 2007). The credibility of qualitative data (sometimes compared to internal validity in quantitative research) is improved with prolonged and persistent interactions, triangulation, peer-debriefing, and deviant case analysis. Transferability (often compared to external validity in quantitative research) assesses the extent to which research findings can be applied in other contexts or with

other respondents. Transferability can be improved with thick description (paying close attention to the contextual details), referential adequacy, prevention of premature closure of the data, purposive sampling, and reflexive journaling. In a high quality study, dependability, also known as reliability, should provide confidence that if the study were replicated with the same or similar respondents in the same or similar context, findings would be repeated (Lincoln & Guba, 1985). The dependability of data can be enhanced with an objective dependability audit and reflexive journaling. Some believe that establishing dependability within qualitative data is sometimes unnecessary as there can be no credibility without dependability. Hence, if credibility is established, this finding is sufficient to demonstrate dependability and a separate proof of dependability is not required (Siegle, n.d.). Lastly, confirmability, or the degree to which findings emerge from the research inquiry and not from the biases of the researcher is also important in qualitative research. Confirmability is often linked to the level of objectivity of the researcher and of the research questions. Confirmability can be improved by a confirmability audit and reflexive journaling. The confirmability audit trail should allow the auditor to determine if the conclusions, interpretations, and recommendations can be traced to their sources and if they are supported by the inquiry (Lincoln & Guba, 1985).

Study participants were invited to participate via open public invitation using local newspapers, social media venues, fliers and posters, and word of mouth (Appendix C). Verbal consent was obtained from each participant prior to conducting the interview and each participant was read or received a copy of the research information sheet (Appendix B). It was expected that the majority of the sample population would have a

diagnosis of metastasized cancers but participants with other life-limiting illnesses such as advanced heart disease, kidney or liver disease, or pulmonary disease were also eligible to participate in the study.

Inclusion Criteria:

Participants responding to the call for participation were screened by phone or e-mail for inclusion based on the inclusion criteria below. To be eligible to be included in this study, the participant must:

- Be 18 years of age or older
- Have awareness of their diagnosis
- Have a serious, life-limiting illness including but not limited to:
 - a) A new diagnosis of advanced cancer
 - b) A recurrence of cancer that is progressing or has metastasized
 - c) Advanced, end-stage pulmonary disease
 - d) Advanced, end-stage heart disease
 - e) Advanced, end-stage kidney disease
 - f) Advanced, end-stage liver disease

Inclusion of patients presenting with a life-limiting illness that did not fall under the above guidelines was decided on a case by case basis with input from the thesis committee. As the needs of patients less than 18 years of age may differ from adults, patients had to be at least 18 years of age to participate in the research study. In addition, patients who were unable to consent for themselves or who had documented cognitive impairment were excluded from participating in the study as it would make it difficult to interview and ask questions about their experiences. Cognitive impairment was determined during the pre-screening conversation and was ultimately a judgement call by the researcher after talking to the participant. If the participant was able to communicate

and express their thoughts and point of view clearly, they were determined to be cognitively appropriate for the study.

Sample size:

Ideally, data collection would continue until there was saturation of themes. Saturation of themes within a data set is the point at which no new information or themes are observed in the data (Given, 2008). It was estimated that approximately 6-10 interviews would be conducted during the course of this research study before saturation occurred. However, recruitment was challenging and only three study participants were ultimately recruited for the study. Six additional people responded to the call for participants who did not meet the study criteria either because of their age (<18 years old) or because although they had serious health conditions, the end of their life was not imminent. Some serious health conditions that were excluded from the study were idiopathic blood clots in an otherwise healthy 40 year old male, severe asthma, and a benign adrenal tumor. Two parents offered to discuss their child's experiences having leukemia and neuroblastoma but these subjects did not meet the age requirement. In addition, one participant agreed to discuss his experience having Stage IV lung cancer but he was unable to schedule an interview due to rapidly failing health and he ultimately died before being interviewed.

Ultimately, only three participants met the inclusion criteria and were able to be interviewed for the study. As qualitative phenomenological data focus on the depth and richness of the patient experience through detailed interviews, the number of participants needed to get in-depth, comprehensive data is often much smaller than in quantitative research. As outlined by Gerrish & Lacey, 2010, sample size in qualitative research

studies is comparatively small (often under 50 participants) and the quality of the data collected is evaluated continually throughout the research study to ultimately determine adequate sample size.

Interview Questions:

The interview questions proposed for this study were investigator-developed to capture data specifically relating to the patients' knowledge of the term prognosis, the patients' experience and perception of their own prognosis, and to assess the communication of prognostic data between health care provider and patient. The interview questions were designed to be non-leading as to not influence the participant answers in any way. The questions were validated for content and independently reviewed for researcher and literature bias by two independent, doctorally-prepared nurse researchers as well as one oncologist. Questions were re-worded or re-phrased several times in order to best elucidate the experience of the participants. The interview guide is attached as Appendix A.

As part of the interview process, the interviewer initially collected basic, non-identifying demographic information such as age, gender and illness, and then broadened the questions to explore the patients' perspective on their experience of knowing and understanding prognostic information. The questions then moved on to explore the patients' perspective on provider prognostication and patient-provider conversations pertaining to their illness. During the interview, follow-up questions were asked of study participants for clarity or explication as noted by the "prompts" in Appendix A. No data identifying the patient were collected.

Data Collection:

Beginning February 24, 2015 patients diagnosed with serious, life-limiting illnesses per self-report were invited to participate in the study. Participants who responded to the call for study participants and who met the inclusion criteria were interviewed by phone or in person at a location of the participants' preference. At the time of the interview, the researcher introduced herself and explained the study purpose in more detail as outlined in Appendix A. Prior to beginning each interview, verbal consent was obtained from each participant (Appendix B). The researcher also stressed the anonymity of the research study data and assured the participants that any data (electronic, paper, or audio recordings) would be destroyed once the study was complete. All interviews (including the phone interview which was conducted on speaker-phone) were audio-recorded using a hand-held voice recorder and the conversations were transcribed using a paid, professional transcriptionist. Data were collected from February 24, 2015 until June 23, 2015.

Data Storage and Confidentiality:

All data were held in strict confidence. Transcripts of interviews, paper data, field notes, as well as audio recording were stored in a locked file cabinet at the researcher's home. Any electronic data were stored on the researchers personal computer which is password and firewall protected and not used by others. Participant data were coded by numbers (i.e., #1, #2, #3, etc) and participant names were not collected or stored. As all transcriptions were time-stamped, recorded data was compared to transcribed data for accuracy.

Data Analysis:

Demographic data such as age, gender of the patient, and type and stage of illness/disease that were collected as part of the study were grouped and analyzed in aggregate. All interviews were transcribed verbatim by a paid, professional transcriptionist and interpretive phenomenological analysis as previously described was used to help to identify themes and sub-themes within the data. All transcriptions were read and reread in detail for an overall understanding and then interpretive analyses was composed by the researcher. As the researcher read each transcript, she kept detailed notes on each transcribed interview, noting any key words, feelings, or statements that seemed important to understanding the patient experience. The key words, feelings, and statements were compared across transcribed interviews and commonalities and differences were noted and categorized. As the analysis developed, emerging data patterns were sorted, categorized, and catalogued as potential themes. The transcripts were then re-read and re-analyzed in their entirety for text that might support the potential themes that were identified during the first analytical iteration. The second iterative process added more depth and support to the potential themes until four independent themes emerged. As new data were collected, the researcher continually read and re-read the transcripts, analyzed the key words, feelings, and thoughts, and reinforced themes and concepts throughout the iterative process.

The benefit of using an iterative method such as the hermeneutic circle is that the research begins with raw data and through constant comparisons to collected data, themes and concepts emerge. As themes are recurring patterns of meaning (ideas, thoughts,

feelings) that are pervasive throughout the transcribed text and are likely to identify something that is meaningful to the participants (i.e. an object of concern, topic of some importance) Hammersley (2007) warns that there are no clear steps which should be taken to guide the analysis of rich qualitative data and instead stresses the importance of thinking about the data and becoming sensitized to it. This iterative and interpretive phenomenological method to data analysis also lends itself well to being submerged in the data and sensitization.

CHAPTER 4

Results

A variety of experiences and perspectives were shared during participant interviews. In total, three individuals with a cancer diagnosis participated in interview sessions. The interviews lasted approximately one hour each, were recorded and transcribed verbatim by a paid transcriptionist and all identifying data was coded to ensure anonymity. All study participants were female.

Table 1: Study Participant Demographics

| Name | Age | Diagnosis | Treatment |
|----------------|------------|---|---|
| Participant #1 | 64 | Lung Cancer, Stage IV | Chemotherapy, Radiation, Experimental Trial Drug |
| Participant #2 | 44 | Breast Cancer, Stage II, ER+ | Unilateral Mastectomy, Chemotherapy, Radiation, 5 years Tamoxifen |
| Participant #3 | 52 | Breast Cancer, Stage IV, Pleomorphic Invasive Lobular Carcinoma | Double Mastectomy |

Using the techniques outlined in the methods section, several themes emerged from the data: 1) patients have a desire for prognostic information as it relates to their illness, 2) prognostic information informs treatment choices, 3) patient experiences are unique and difficult to generalize using statistics and, 4) patients feel connected to nurses involved in their care. In keeping with the chosen method of phenomenology, themes represent common elements of the participant experiences; individual excerpts are included to explicate the themes.

Theme 1: Patients have a need for prognostic information

All study participants expressed wanting as much information as possible about their disease state. Specific to knowing about their prognosis, all participants thought it was important to know as much as possible and information gathering was an important part of the cancer journey.

I'm not morbid, but I want to know. I want to know what my chances are. What should I do? I wouldn't want somebody beating around the bush ---I want to know what to expect. You know, what am I going to do? How am I going to lead my life? You can't lead your life unless you kind of know. *Participant #1*

I always—I always want to know things and educate myself as much as possible on what's going on. It helps me to make decisions based on the whole picture rather than the pieces. I'm definitely in favor of it, because I don't see how you can make an informed decision about your life if you don't have all of the cards on the table.

Participant #3

Participant #3 also expressed strong opinions on the omission of information or withholding of information during conversations with her health care providers.

I was horrified by what the doctors did not tell me, and they got on my page about that because I was shocked. I was shocked at what they didn't tell me. And I felt that that is not how you treat a person. You have to give them all of the information, not what you deem necessary so that you can treat them with chemo. I take this to another level where most people don't, but I think that—I think that I feel it's important to know everything, but in fairness of the doctors, a lot of people don't want to know.

Likewise, participant #1 felt that her health care providers were open and honest with her, but questioned if they were giving all information or just answering questions that were asked directly.

All of my healthcare providers have been extremely open with me. Everybody I've dealt with, they've answered every single question I've had, and they told me right up front what they think.

When asked "Do you think that your health care provider would tell you something if you didn't ask them?" the participant answered:

I don't think that they would, no. I think a lot of people are afraid to hear that, that total prognosis. I think they're

afraid of [hearing] you've only got three years left. That's not much time.

Participant #1 and #3 expressed that they actively did a lot of independent research on-line and via networking and second opinions on their disease, their diagnosis, their prognosis, and treatment options. They felt it was very important that they educate themselves about their disease and not solely rely on their health care providers for information. Although they looked to their healthcare providers for information, they also were very motivated to research their disease independently. The second study participant also expressed a desire to know her prognosis.

I would want to know. I mean, I have two girls. So, you know, of course I would want to know, you know, like if I have until tomorrow or... [longer]. I think I would rather know if I had three months but you know, if I had five years, I think I would want to know too but not as bad as if I had three months.

The second study interviewee also had questions about her current state of health and desired more information from her provider.

Am I like, in remission or what? You know, like, people are asking me, how are you doing? I'm like, I guess I'm in remission?

It would be nice to know. *Participant #2*

Participant #3 shared that the word prognosis itself never came up in her conversations with her health care providers. The closest she got to talking about prognosis was when she asked her provider “Is there anything else you want me to know in terms of what may happen?” And he said, “You know what, I want you to go and live your life.” This is further testament that even the most seasoned of health care providers may find it difficult to broach the subject of prognosis, especially when the prognosis is poor.

Theme 2: Prognostic information informs treatment choices

All study participants agreed that knowing their prognosis affected their treatment plan. For study participant #1, after receiving two rounds of high dose chemotherapy only to have the cancer return within three months with no improvement in her prognosis led her to decline further chemotherapy and to seek experimental clinical trial therapy.

After going through the two bouts of chemo and it came right back again, I wasn't going to do it [chemotherapy] anymore because it--- the prognosis hadn't changed. I figured well, there's got to be something out there.

Whether or not it [experimental therapy] was going to work, I didn't know, but at least I was going to try it, because I was not going to do any more chemo. If tomorrow they told me this [experimental therapy] wouldn't work, I don't think I would go back to the chemo.

Participant #2 felt that there wasn't really much choice in her treatment plan offered from her provider other than deciding whether or not to have a lumpectomy, a single or double mastectomy.

I think they were really pushing to have both breasts done, but I'm like, I'll deal with that later on. There was nothing in the left breast, but to me, it seemed like they were pushing for both. [Chemotherapy] wasn't really an option. The chemo and radiation they said, you're going to do these. They said, this is what you're going to do; you're going to do chemo, radiation and the pill [Tamoxifen].

Participant #2 spoke more hypothetically about how her prognosis might affect her choice of treatment if her prognosis was worse. Speaking hypothetically and assuming she had been through some unsuccessful treatments, she states:

I would try to fight. I would fight for it, you know, I'd still do something [treatment] if there was something for it. Anything the doctors thought might help.

Participant #3 also felt pressure to begin a therapy that she was not sure about.

The doctors very much wanted me to do it [chemotherapy] because they had to act aggressively. I kind of butted heads

with all of them because they all wanted me to do this
chemo.

Participant #3, who chose to have a double mastectomy but no further chemotherapy or radiation because she felt her body couldn't handle it and it would shorten her life stated:

I know what my prognosis is, and deep down inside, I think I always knew that it was kind of too late for any kind of treatment, and I –you know, I was trusting my instinct and going with it. I already knew in my heart and soul that if I did the chemo, I would probably end up dying sooner rather than later. There wasn't any benefit that the chemo or the radiation was going to give me that I didn't already have because I didn't want to be puking and spending my time in the bathroom all the time. I didn't want to lose my hair and weigh 90 pounds so that that was the last image that my children had of me. There were certain things that I didn't want because there was no benefit that the chemo was going to give me. Chances are there would be absolutely zero benefit. The only thing it would do is add to my suffering.

Theme 3: Patient experiences are unique and difficult to generalize with statistics

All participants expressed some degree of concern about balancing all of the information about their disease and prognosis without feeling like a statistic. The participants seemed to associate statistics and prognosis to some degree and for some, the term prognosis had a negative connotation partly because it was linked in their minds to statistics and they did not want to feel like a statistic. Each participant felt that their experience was unique and difficult to predict with statistical analysis. The uncertainty of predicting the course of someone's life was unsettling, especially when the patient is feeling well. Two of the participants wanted to know in broad strokes how they were doing, while one only wanted to know when they had a short amount of time left to live.

When I've got about three months left, then I'll start planning for what's going to happen after. They should be able to tell me something, I think, as we get closer. *Participant #1*

To make a long story short, ultimately, I decided I wasn't going to do it [chemotherapy] because instead of listening to statistic prognoses, I listened to my gut instinct, and I think that's really why I am still here. I think if I had done the chemo or any radiation that I would have, I would have passed by now. *Participant #3*

The oncology doctor...I met with her one time for an hour. I was so disappointed at the end of that meeting. It helped make it easier for me to make my decision in the long run, because I did not care for her presentation. She used this whole computer system to determine my life. You know, that's where they come up with some of the prognoses, in terms of, you could have this long based on this. I think probably when it comes to prognosis, I am too much of a realist for that word, because you know, that's like trying to forecast the future, and I've learned a long time ago, you can't do that. I fully understand that word prognosis and what it's all about, but for them to put a number on it, it wouldn't work for me. It would have been something negative in my mind. You know, kind of ticking in my mind. And I know that some of the prognoses are done through scientific facts of this, this and this and this, but it's still a guessing game. Prognosis is still a guess and my life is more than a guess. I knew if I had a number, you know, my mind would—it would keep popping up in my mind. Like I said, when I've knocked on Heaven's door, you know, I've been that close, but my time is ---my time is not up until my time

is up, and nobody knows when that is, not even me.

Participant #3.

Theme 4. Connection to nurses

All three participants discussed the key role that nurses played in their health care, noting a special closeness they felt with their nurses. Participant #3 noted that she called a favorite nurse at a pivotal moment when she finally decided not to try any further treatments:

It's like my gut instincts, my God or whatever, whatever force was driving me, I picked up that phone. I called Debbie, the nurse, because I loved her, and I left her a voicemail, basically, stating that I was not going to make the appointment. You know, I've decided I'm not going to do the chemo, and when I hung up the phone, it was the first time since my diagnosis that I felt like I could breathe.

Participant #2 really appreciated the timeliness and the efficiency of the radiation nurses stating:

They are great. They are great. I mean, like, it's just funny because you know most hospitals or doctors you go to, they're like, be here at 9:30. You get there at 9:30 and wait a half an hour in their waiting room and then, you know, it's another 10 minutes sitting inside. But there [radiation oncology], you know, they want you there 10 minutes early

so that you can be on the table at 9:30. You're in and out,
which is so nice.

Participant #1 had a close connection with her nurse coordinator who also cared for her husband during his cancer journey years ago.

In fact, yesterday I was down at the hospital and I ran into my –the coordinator who coordinated my [care] and he gave me a big hug. It was so nice to have him as my coordinator, and you know, to line everybody up and to tell me about this doctor and that doctor and what was going to happen, and boy, he was so invaluable.

Participant #1 also noted a positive experience with her chemotherapy nurses.

[I had] a very positive experience all around, and you know, the care providers are a good share of that. Nurses included. I mean, some of the chemo nurses that I met while I was down there, I mean, goodness. There were two nurses, as I come in, they take me and usually one of them would get it [IV access]. One would usually get it and if she couldn't, she'd get the other one. Boy, I had forgotten about those things.

The connection, appreciation, and fondness of the nursing staff involved in the patients care was unsolicited information and not part of the interview

questions or aims of this study. None of the study participants mentioned that any of their nurses participated in the delivery of prognostic information or played a key role in the prognostic experience. However, the important role that nurses play in the lives of patients going through cancer diagnosis and treatment was evident in the conversations recorded as part of this research study and could be the subject of future nursing research.

Although a small study is presented here, the current research study meets some but not all criteria for high quality qualitative data. Credibility of the data was enhanced through the prolonged and detailed conversations with the study participants. The dependability of the data was improved with a dependability audit and detailed reflexive journaling. The confirmability of the data was enriched through carefully worded interview questions to guide the interview without researcher or literature bias. The transferability of the data was enhanced through purposive sampling and reflexive journaling. The small sample size was a hindrance to assessing the overall transferability of the data to other populations.

CHAPTER 5

Discussion

Hallmarks of high-quality qualitative research include rich, substantive data with strong evidence for researcher inferences and conclusions. While the intent is to report the lived experiences of those involved in the inquiry, it is recognized that the researcher is intertwined in the portrayal of this experience. The overarching goal of qualitative research is enhanced understanding to provide a meaningful account of the complex perspectives and realities studied.

There was thematic congruence between this study and previous scholarly work, especially illuminating the patients' desire and need for information during their illness (Hagerty et al., 2004; Hagerty et al., 2005), a desire for patient autonomy and making informed choices (Beauchamp, 2009; Johnson, 2006), and a general avoidance discussing prognosis by both health care providers and patients (N. A. Christakis & Iwashyna, 1998; Daugherty & Hlubocky, 2008; Rich, 2014). Key findings from this research include: 1) patients want to know as much information as possible about their illness, and they may seek information from many sources, 2) patients understanding and acceptance of prognosis informs treatment choices, 3) patient experiences with life-limiting illness are unique and difficult to generalize with statistics, and 4) nurses play a key role in the care of patients during a serious health crisis.

Theme 1: Patients have a need for prognostic information

All study participants expressed a strong desire to gather as much information about their health condition as possible, including details of their prognosis. Two of the three participants offered that they “took matters into their own hands” and began an almost obsessive quest for knowledge that included on-line research, obtaining second opinions, reaching out to friends, researching clinical trials, as well as using the hospital based resources available to them such as case management, nurse navigators, nurses, radiologists, and oncologists. The second participant did not mention specifically this total immersion approach to information gathering but relied heavily on the information provider by her health care providers. Independent of how information was obtained, study participants expressed a heightened need for information about their illness, diagnosis, treatment, and prognosis, especially early in their journey. This was in line with recently published data showing that providing information about treatment side effects, extent of the disease, prognosis, and chances of cure can help meet patients’ informational needs (Lin et al., 2014).

The implications of this finding could prove to be important. According to the patients in this study, patients with life-limiting illness may seek as much information as possible. The quality of the information that they receive on the internet or from friends is questionable and it may vary according to the person and where the patient is in her treatment. Hence, the information that they receive from their health care provider should be thorough and comprehensive. As the literature shows that prognostication is difficult to initiate (N. A. Christakis & Iwashyna, 1998; Daugherty & Hlubocky, 2008;

Gawunde, 2010), the health care provider should offer to share information, even if the patient does not specifically make a request for prognostic data. Health care providers may also sometimes feel the need to withhold or delay information with the thought that they are giving the patient time to absorb some of what is going on or out of fear of overwhelming the patient. Data from this study and others (Lin et al., 2014; Jennifer W. Mack et al., 2012; Nelson et al., 2011) suggests that all information should be offered to be shared between provider and patient, even if it is bad news or sensitive information. If the patient feels that information was withheld or not discussed openly, they may feel betrayed, angry, or mistrust of the provider. It is unclear from the conversations with participant #3 if the provider had information that he/she was unwilling to share, if the provider just didn't think to share it with the patient, or if the patient received the information but was not able to process it. Further confounding interpretation of this theme, is the subjectivity of each patient's experience. We have no way of telling for sure what exactly was said between provider and patient. The patient's interpretation of the provider's words may be skewed. The patient may not be able to understand or process all of the information given to them and in hindsight, is reporting that they were not given the information. There is certainly a wealth of information to be relayed and information that might be deemed crucial to one patient may not seem important at all to another. These considerations highlight the need for continued open communication and repetition of literature supported prognostic information in provider/patient interactions.

Theme 2: Prognostic information informs treatment choices

All participants felt that knowing one's prognosis was important for making downstream decisions about their future. Participants felt that it was important to know about their prognosis in order to choose treatments (or not), mitigate pain, have discussions with family, plan for the future, and map out the tasks to be completed while the patient was still alive and feeling well. Two of the participants discussed that knowing they had limited time to live spurred an effort to "get their affairs in order", which meant setting up trust-funds, making a will, updating advanced directives, sorting through a life-time of belongings, and doing the things they have always wanted to do while they were still feeling well.

Knowing one's prognosis helps to inform the next step in the treatment process, which is in line with previous work in this field (Daugherty & Hlubocky, 2008; Glare & Sinclair, 2008). In this study, all patients made treatment decisions based on many factors, one of which was their prognosis. Participant #1 chose to pursue experimental therapy after failing first line and second line chemotherapy with no change in prognosis. Participant #2 chose standard of care chemotherapy, radiation, and hormone therapy based on a favorable prognosis with this regimen. The third study participant chose a double mastectomy and no further treatment based on her poor prognosis and values surrounding her life-threatening illness. If we extrapolate from the limited sample in this study, it seems that patients with a more favorable prognosis are more willing to attempt standard treatment without question. Patients with less favorable prognoses seem to be

more willing to try experimental therapies or opt for no therapy and allow for the natural progression of the disease (Mack et al., 2013; Matsuyama et al., 2006).

A sub-theme of theme #2 dubbed “feeling pressure to pursue treatments” emerged as all study participants expressed (unsolicited) feelings of pressure to pursue treatment that they ultimately chose not to try. Participant #2 interpreted pressure from her provider to have a double mastectomy but opted for a right breast only mastectomy. Participant #3 sensed pressure to try chemotherapy and radiation after her double mastectomy and ultimately decided not to pursue chemo or radiation. Similarly, participant #1 felt out of options after two high dose chemotherapy treatment failures and sought experimental therapies offered at outside institutions which she brought forth to her oncologist as options to pursue. Certainly in all three of these cases, self-advocacy and autonomy were critical pieces in treatment decision making and treatment paths.

Theme 3: Patient experiences are unique and difficult to generalize with statistics

When study participants were asked to specifically discuss their feelings around their prognosis, conversations flowed to discussions of statistical probability of survival and each participant expressed their dislike for the use of statistical models to predict their death. Participants expressed the desire for acknowledgement of their unique health situation and they were eager to discuss their individual journey from initial cancer diagnosis, through various treatments to the present day but were less eager to discuss the topic of prognosis specifically. Discussions specifically targeting prognosis were strained. Part of the strain stemmed from a linkage of the term prognosis with statistics. Perhaps part of the difficulty discussing prognosis also lies in the uncertainty of the

future, especially when compared to the factual nature of recounting the events of the past surrounding initial diagnosis and/or treatment history. Previous work has shown that there is a general unease amongst health care providers in prognostication given the inaccuracy of prognostic data available (N A Christakis & Lamont, 2000; Hui et al., 2011; Thomas et al., 2009). It is very likely that the uniqueness of each person's experience played an important role in the difficulty discussing prognosis as well.

In the context of both themes #1 and #2, it is interesting to think about how the uniqueness of each patient experience complicates prognostication for the health care provider. Patients want information, including prognostic information and the information that they receive informs the treatments that they will choose. However, a few clear dichotomies exist: 1) Patients want prognostic information but they do not want to feel that they are only a statistic, and 2) Patients want treatment information but they do not want to feel pressure to choose one treatment over another. It is difficult to have frank prognostic discussions with patients without mentioning the provider's best understanding of the probability of survival or therapy-specific statistics of survival. Likewise, it is a fine balance to give information about options for therapies without applying pressure to choose a specific therapy or "the best therapy". Ideally, it would be best to present treatment options, side-effect information, functional ability, outcome data from the literature, as well as the clinical picture with no treatment, free of provider bias or preference for one treatment over another. In some cases however, the patient wants to know hypothetically what the provider would do if he or she were in the patients shoes, which also complicates the equation.

A sub-theme of theme three emerged from the data: Prognosis is difficult to discuss. Conversations specifically targeting prognosis were found to be difficult to initiate and sustain. In general, participants were hesitant to discuss prognosis specifically and the researcher found it surprisingly difficult to speak directly about prognosis even within the confines of a research study designed to discuss prognosis. There was a predominant feeling of awkwardness discussing questions pertaining to prognosis. There are several plausible explanations for these feelings of unease. Perhaps participants felt “quizzed” or “put on the spot” when asked specifically what they understood about their prognosis. Perhaps they hadn’t thought specifically about prognosis for a while and it was a reminder to them of their reality or of their mortality. Perhaps the unease was related to the sheer number of questions directed specifically at prognosis or how the questions were posed by the researcher. The researcher tried to emphasize that there were no right or wrong answers to the study questions however, from the researcher’s perspective, it felt very insensitive to focus so intently on prognosis during the interview. Conversely, it felt much more comfortable talking about diagnosis, diagnostic time-frames, and treatment history which is a sentiment reflected in the literature (N. A. Christakis & Iwashyna, 1998; Daugherty & Hlubocky, 2008). To the researcher, it felt surprisingly irrelevant, unimportant, and insensitive to discuss prognosis so pointedly and repeatedly in order to assess what the patient knew or wanted to know about their prognosis. In addition, the scripted verbage felt repetitive at times, as sometimes the patient had elaborated freely during a previous question and touched upon topics addressed in the next few questions prior to hearing them.

Theme 4. Connection to nurses

All study participants discussed feeling supported by the nurses who have been involved in their care. In particular, study participants mentioned one or two nurses who they felt a close bond with and who had supported them through their cancer journey. The nurses mentioned were instrumental in helping the patient navigate the complicated health care landscape and they were described as “experts” and the “go-to” people when the patient had a need. The nurses were accessible, offering their expertise and knowledge to the patient, often via a direct phone line so that the patient did not have to wait for their answer very long. Sometimes the knowledge imparted was technical (skilled at port-access, IV access, etc.), sometimes the support was emotional (supportive listening, offering encouragement or prayer), and sometimes the support was logistical (navigating appointments and specialists, coordination of care). Importantly, the connection to nurses that the study participants expressed likely made a difficult situation easier for the patient, allowing for less stress and anxiety. This data is supported by other studies highlighting the important role that nursing plays for the patient in the end-of-life setting (Bridges et al., 2013; Hawley & Jensen, 2007). These studies portray nurses at the “hub” of the organization, navigating both the provider and patient technical, informational, and emotional needs.

Strengths.

Qualitative studies provide a depth of information and are useful for studying complex phenomena using relatively few cases. Cross-case comparisons and iterative data analysis allow for a better understanding of people’s personal experiences of

important issues such as end-of-life. In addition, qualitative approaches are well suited to elicit stakeholder's needs and in the context of this research study, a patients need for information and their understanding of prognosis. The credibility of the data set is not in question, even with the small sample size. It is the belief of the researcher that the data collected is reflective of the whole patient story. The depth of the conversations, the investment of time and energy of the participants, and the prolonged, open dialogue added to the credibility of the data. In addition, the confirmability of the data is likely solid due to the rigor of the questionnaire used to direct the interviews as well as the confirmability audit provided by the thesis committee.

Limitations.

This study has several limitations that may hinder the interpretation of knowledge gained regarding ones' prognosis when diagnosed with a life-limiting illness.

First, only three individuals contacted the principal investigator who met the study criteria and were interviewed. Therefore, some potential themes that emerged within individual interviews had to be excluded because they were not found within other interviewee's transcribed data. Further, the small sample size of this study did not allow the opportunity to assure saturation of all themes. In this way, it cannot be determined whether the themes would have been found among other individuals' experiences not interviewed for this study and hence, the transferability of the data remains in question. Steps to enhance transferability such as thick descriptions, purposive sampling, and reflexive journaling were employed.

Recruiting participants was challenged by the fact that people facing serious health issues may be too stressed or uncomfortable to participate in research that involves talking to a complete stranger about very sensitive topics such as end of life. Additionally, it was found that the term prognosis evoked a negative feeling or feeling of unease for the study participants, which also may have contributed to the small sample size. In future studies, recruitment of subjects might be improved with a written survey rather than face to face or phone interviews. It appeared that people were much more willing to discuss their prognosis face to face when their prognosis was good or after they had completed a therapy successfully. Patient reflections on such sensitive and personal journeys might be more forthcoming if done anonymously or in writing. Another strategy that may improve study recruitment and selection bias would be to offer a small incentive (monetary, services, or gift cards) in exchange for participation.

Arguably, selection bias makes the transferability of these data are questionable. Given the small sample size, we cannot assume that all patients diagnosed with life-limiting illnesses are prepared for an onslaught of information. It seems reasonable that some patients would like to control the timing, quantity, and type of information they wish to hear. That said, there are improvements to be made to these sensitive discussions, starting with asking the patient what they would like to know. For patients who want information, including prognostic data and starting prognostic conversations sooner rather than later appears to be beneficial.

Implications for Advanced Nursing Practice.

The Nurse Practitioner Core Competencies identified by the National Organization of Nurse Practitioner Faculties, outline several essential functions for nurse practitioners (Hamric et al., 2014). In particular the core competencies outline how nurse practitioners improve the quality of health care delivered through addressing the needs of potentially vulnerable populations such as the terminally ill and other stakeholders (2014). This research study and previous literature within the field of prognostication illuminate several ways that health care providers have contributed to positive and negative patient experiences receiving healthcare. While more research is needed in this field of study, the aims of this research, 1) to explore the patient understanding of prognosis and to illuminate the experience of having or not having prognostic information in people diagnosed with life-limiting illnesses, 2) to investigate understanding and significance of the term “prognosis” to the patient, 3) to identify how prognosis may or may not affect future treatment choices for the patient, and 4) to further understand the experience of prognostic communication between provider and patient, are consistent with the core competency of illuminating the needs of a vulnerable population, improving patient-centered care, and working in partnership with others to provide optimal care.

Based on this research, improvements in care to patients with a terminal illness could be made. Provider awareness that patients with a terminal illness have acute needs regarding information gathering is important. In addition, providers could improve their care by collaborating with experts in the field of end-of-life and palliation to improve the

patient experience. Certainly, ensuring that providers ask patients about what they need and what they want to know regarding not only their diagnosis and treatment, but also about their prognosis would be a positive step. It is clear that prognosis is not an easy subject to broach, so an awareness by the provider that the patient may have difficulty bringing up the subject is a key finding.

APRNs are in a unique position to affect policy and to make significant changes to how end of life care is currently administered to patients. There is growing evidence that providing concurrent hospice care and curative care is beneficial to the patient and economically wise (Parikh, Kirch, Smith, & Temel, 2013; Spettell et al., 2009). For example, among Aetna beneficiaries participating in the Compassionate Care Program, patient use of hospice care increased greatly, and acute care and critical care utilization decreased for an overall cost savings, increases longevity, and better self-reported quality of life (Spettell et al., 2009). APRNs with specialty expertise in end of life, oncology, chronic disease, and palliative care are at the front lines of health care reform, giving expert testimony and lobbying for greater access to hospice and for broader coverage for palliative services. It is becoming clear that early integration of palliative care in combination with life-prolonging treatments has benefits and many APRNs are leading that policy change nationally.

APRNs are also uniquely suited to integrate primary care and specialty care. Coordination of care after a life-limiting diagnosis has been identified as a huge burden to the patient (Berry, Rock, Smith Houskamp, Brueggeman, & Tucker, 2013; O'Malley & Cunningham, 2009). Working as part of the integrated health care team, the APRN is

able to ease some of the patient burden with knowledge of the organizational system, the key players who will be involved in the patients care, the medical/scientific knowledge to share with the patient, as well as specialty training in end of life care, chronic disease, and palliative services.

Although data saturation was not reached, the practice of performing the research study within a potentially vulnerable population reflects the nurse practitioners' commitment to the core competencies of practice inquiry, scientific inquiry, leadership, patient centered care improvement, and partnerships with others.

Recommendation for Future Research.

Future research could examine larger participant pools to determine whether the themes identified in this research are identified within an expanded data set. Furthermore it might be valuable to compare provider perceptions of prognostic information given to the patient perspective. Beyond the research questions investigated in this thesis, future qualitative research to further understand the meaning of prognosis to patients, how the uniqueness of each experience intersects with knowledge of ones' prognosis, the negative connotation of the term prognosis, the perceived relationship between statistics and prognosis, and the reasons that people are uncomfortable discussing prognosis could be examined. The patient perspective is sparse in the prognostic literature and should be explored further. Overall, prognostic data and the sharing of sensitive information between health care provider and patient offers many opportunities to understand how to improve health care to patients facing life-threatening illnesses.

In retrospect, it would have been insightful to ask study participants directly if it was uncomfortable for them to discuss prognosis and if so, ask them if they could elaborate freely on why they felt discomfort. The many plausible reasons for the difficulty in discussing prognosis could certainly be the focus of future research, as there are very few studies aimed specifically at understanding the patients' perspective on why prognostic conversations are so uncomfortable and often delayed or avoided.

Conclusions.

This study presents themes based on the healthcare experiences of patients living with serious life-limiting illnesses. Four themes were identified: 1) patients have a desire for prognostic information as it relates to their illness, 2) prognostic information informs treatment choices, 3) patient experiences are unique and difficult to generalize using statistics and, 4) patients feel connected to nurses involved in their care. The intent of this research is that the themes identified may ultimately contribute to the knowledge base by supporting healthcare providers in improving end of life communication. These data suggest that patients want information, they want to be treated as an individual and not a statistic, and that prognostication is important as it affects downstream decisions. Although admittedly difficult, an effort to improve prognostic communication will likely improve the health care experience for patients as they navigate a serious health issue. More research is needed in this field to better understand how patients interpret and synthesize prognostic data and how prognostic communication between health care provider and patient can be improved.

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Appendices

Appendix A: Interview Guide

Erika A. Currier

Understanding the Importance of Prognosis to People With Life-limiting Illnesses: A Qualitative Research Study

Conducted by: Erika A. Currier, BA, RN, as part of fulfillment of requirements for Masters of Science degree in Nursing, 2015.

University of Vermont

Department of Nursing

Burlington, VT 05401

Appendix A: Interview Guide

Introduction:

My name is Erika Currier. I am a nurse and a graduate nursing student with a special interest in quality-of-life issues and palliative care. I am conducting this research study because I am interested in knowing more about how patients who have been diagnosed with serious, life-limiting illnesses (also previously called “terminal illnesses”) understand their prognosis. This study aims to investigate the patient’s understanding of the term “prognosis”, the significance of the term “prognosis” to the patient, and how prognosis may or may not affect future treatment choices for the patient. In addition, this study aims to further understand how and when prognostic communication between provider and patient occurs.

You are being invited to take part in this research study because you understand that you have been diagnosed with a life-limiting illness and you are at least 18 years of age. You have responded to a “call for research participants” and have contacted me to participate in the study. I would like you to know that taking part in this study is completely voluntary you are free to not answer any questions or withdraw from the study at any time. You may choose not to take part in this study, or if you decide to take part, you can change your mind later and withdraw from the study.

If you agree to take part in this research study, then you agree to a one-time interview where I will ask you questions pertaining to your knowledge of your prognosis, your feelings about your prognosis and about the communication of your prognosis to you by your health care provider. The interview will likely take less than one hour and will be audio-recorded. **By participating in the interview, you are hereby consenting to be in the study.**

As a participant in this research study, there may not be any direct benefit for you; however, information from this study may benefit other people now or in the future.

As a participant in this research study, I do not expect there will be any risk to you. However, due to the sensitive nature of the topic being discussed, you may feel some level of discomfort or anxiety. If at any time you would like to stop, pause, or withdraw from the interview, you may do so without any consequence. Should you feel the need to process any thoughts or feelings that come up for you during your participation in the study, a list of local counselors are available to you and can be found at <https://therapists.psychologytoday.com/rms/state/VT/Burlington.html>

All information that I collect during this study will be protected and held securely in confidence. I will not collect any information that will identify you to further protect your confidentiality and to avoid any potential risk for an accidental breach of confidentiality. All information collected from you during the course of this study will be stored without any identifiers. No one will be able to match you to your answers. I will only ask for your first name (and you may use an alias if you choose), your age, and your diagnosis or life-limiting illness. All data will be stored in a locked file cabinet throughout the course of the study and all data will be destroyed at the termination of the study.

There will be no costs to you for participation in this research study and you will not be paid for taking part in this study.

If you have any questions about this study now or in the future, you may contact me, Erika A. Currier, RN, at the following phone number 858-231-3345 or by e-mail at ecurrier@uvm.edu. If you have questions or concerns about your rights as a research participant, then you may contact the Director of the Research Protections Office at (802) 656-5040.

Are you ready to begin the interview?

If yes, I will begin recording our conversations now (*begin recording*).

1. Can you please state your age?
2. Can you please tell me about your diagnosis or illness?

Prompt (if needed):

- *What is your diagnosis?*

- *Do you recall when you were first diagnosed?*
- *For cancer, do you have metastasized disease or has it spread to other parts of your body?*
- *For cancer, what therapies have you tried (chemo, radiation, stem cell transplant, other?)*

3. What is your understanding of the term “prognosis”?

Prompt (if needed):

- *What does prognosis mean to you?*
- *What does a poor prognosis mean to you? Good prognosis?*

Everyone hears this: For the purposes of this research study, we are going to define prognosis as a prediction of the chance of recovery from a disease. Does this make sense?

4. In light of the definition of prognosis that I just gave you, can you share with me your understanding of your own prognosis as it relates to your illness?

Prompt (if needed):

- *What is your understanding of your chances of recovery from your illness?*
- *Have you researched life expectancy projections?*
- *Have you discussed life expectancy projections?*
- *How long do you think you have left to live?*
- *Do you expect to be alive in two weeks, one month, 3 months, 6 months, 1 year, two years, five years?*
- *Do you expect that any treatment you are currently having can cure your disease/illness?*
- *Do you expect that any treatment you may have in the future can cure your disease/illness?*

5. Do you feel that having information about your prognosis is important? If so, why? If not, why?

Prompt (if needed):

- *How would having a poor vs. good prognosis change your plan for treatment?*

- *How does knowing your prognosis make you feel?*
- *How has having information about your prognosis has guided your treatment decisions?*

Everyone hears this: For the purposes of this study, prognostication is defined as the act of delivering prognostic data to patients. Prognostication includes discussions of life expectancy, how an illness or disease typically progresses, chances of recovery from the disease or illness, side-effects of therapies, and estimates of functional ability. Does this make sense?

6. If you have had any conversations specifically about your prognosis with your health care provider, can you share with me your recollection of those conversations? As a reminder, prognostic conversations may have happened more than once over the course of your illness.

Prompt (if needed):

- *Do you recall who initiated the prognostic conversations?*
 - *Did your health care provider discuss with you:*
 - a) The chances or odds of curing your illness*
 - b) Your life expectancy if you receive treatment*
 - c) Your life expectancy if you do not receive treatment*
 - d) the expected course of your disease*
 - e) options for therapies*
 - f) the side effects of therapies*
 - g) quality of life*
 - h) palliative care*
 - i) hospice care*
 - *Do you feel that you had adequate time with your health care provider to discuss your prognosis?*
 - *Have you discussed prognosis more than once? If so, when during the course of your illness?*
 - *If you have never discussed prognosis with your health care provider, why do you think that is?*
7. Over the course of your illness, have you wanted more prognostic information, less prognostic information, or did you feel that you have had an adequate amount of prognostic information?

Prompt (if needed):

- *What are the benefits of knowing your prognosis?*
- *What are the consequences of knowing your prognosis?*
- *What barriers to discussing your prognosis with your health care provider have you encountered?*
- *What benefits of discussing your prognosis with your health care provider have you encountered?*

8. Do you believe that any of the treatments that you have tried, are currently trying, or may try in the future have the potential to cure your disease or illness?

*Everyone hears this: An **advance health care directive** is a legal document in which a person specifies what actions should be taken for their health if they are no longer able to make decisions for themselves because of illness or incapacity.*

9. Do you have an advance directive?

10. Is there anything else that you would like to share with me concerning your feelings about your prognosis?

11. Do you have any further questions for me?

Everyone hears this: The interview is now complete. Thank you very much for participating in this research study. I appreciate your time and candor discussing your illness with me and I wish you the best health and quality of life possible for the future.

Appendix B: Research Information Sheet

Research Information Sheet

Title of Study: A STUDY TO INVESTIGATE THE SIGNIFICANCE OF KNOWING ONES' PROGNOSIS IN PEOPLE DIAGNOSED WITH LIFE-LIMITING ILLNESSES

Principal Investigator (PI): Erika A. Currier, RN

Faculty Sponsor: Judith A. Cohen, PhD.

Funder: University of Vermont Graduate Nursing Department

Introduction

You are being invited to take part in this research study because you have been diagnosed with a life-limiting illness and you are at least 18 years of age. This study is being conducted by Erika A. Currier, RN, a graduate student at the University of Vermont.

Purpose

The purpose of this research study is to explore the patient understanding of their prognosis and to illuminate the experience of having or not having prognostic information in people diagnosed with life-limiting illnesses. Is having knowledge of one's prognosis important? How might having knowledge of or not having knowledge of one's prognosis affect treatment choices? How and when is communication of prognostic information occurring between health care provider and patient?

Study Procedures

If you take part in this research study, you will be asked to participate in one in-person interview. You will be asked questions pertaining to your knowledge of your prognosis, your feelings about your prognosis and about the communication of your prognosis to you by your health care provider. You have the option of not answering questions that are upsetting or too personal and still remain in the study. Your commitment to the research study is one interview session that will likely take less than one hour. The interviews will be audio-recorded and then transcribed to ensure accuracy in your responses.

Benefits

As a participant in this research study, there may not be any direct benefit for you; however, information from this study may benefit other people now or in the future.

Risks

We will protect the information we collect from you during this study. We will not collect any information that will identify you to further protect your confidentiality and avoid any potential risk for an accidental breach of confidentiality. However, due to the

sensitive nature of the topic being discussed, you may feel some level of discomfort or anxiety. If at any time you would like to stop, pause, or withdraw from the interview, you may do so without any consequence. Should you feel the need to process any thoughts or feelings that come up for you during your participation in the study, a list of local counselors are available to you and can be found at

<https://therapists.psychologytoday.com/rms/state/VT/Burlington.html>

Costs

There will be no costs to you for participation in this research study, other than your time.

Compensation

You will not be paid for taking part in this study.

Confidentiality

All information collected about you during the course of this study will be stored without any identifiers. No one will be able to match you to your answers. I will only collect your first name (and you may use an alias if you choose), your age, and your diagnosis. All data, including audio recordings and transcriptions, will be stored in a locked file cabinet throughout the course of the study and will be destroyed at the termination of the study.

Voluntary Participation/Withdrawal

Taking part in this study is voluntary and by participating in the research interview, you are consenting to be in the study. You are free to not answer any questions or withdraw at any time. You may choose not to take part in this study, or if you decide to take part, you can change your mind later and withdraw from the study. If you choose to withdraw from the study, all audio recordings and transcribed data will be immediately destroyed and will not be included in the data analysis. If for some reason this researcher feels it is in your best interest to withdraw you from the study or if for some reason the data you provide is unusable, all audio recordings and transcribed data will be immediately destroyed and will not be included in the data analysis.

Questions

If you have any questions about this study now or in the future, you may contact me, Erika A. Currier, RN, at the following phone number 858-231-3345 or by e-mail at ecurrier@uvm.edu. If you have questions or concerns about your rights as a research participant, then you may contact the Director of the Research Protections Office at (802) 656-5040.

Statement of Consent

You have been given and have read or have had read to you a summary of this research study. Should you have any further questions about the research, you may contact the person conducting the study at the address and telephone number given below. Your

participation is voluntary and you may refuse to participate or withdraw at any time without penalty or prejudice.

If you agree to participate in this study please provide verbal consent. Your verbal consent will be documented in the research records.

Name of Principal Investigator: Erika A. Currier, RN

Address: ecurrier@uvm.edu

Telephone Number: 858-231-3345

Name of Faculty Sponsor: Judith Cohen, PhD

Address: 219 Rowell Bldg, University of Vermont, Burlington VT 05401

Telephone Number: 802-656-3382

Appendix C: Call for Study Participants Flyer

Have you been diagnosed with an illness or disease that may shorten your life?
Do you know your prognosis?

Are you interested in sharing your experience as part of a research study that would help me graduate?

Hello! I am a graduate student at the UVM College of Nursing and Health Sciences and I am conducting an interview-based research study to develop a better understanding people's experience with knowing their prognosis.

- Participants for this study must be over 18 years old
- Have a serious life-limiting diagnosis

Participation in this study will involve a one-time interview (less than 60 minutes in length).
 All Interview data will be kept confidential.



If interested, please contact Erika Currier.

Phone: 858-231-3345 • e-mail: ecurrier@uvm.edu

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