

"Teeter-Tottering Between Hope and Despair":
Fathers' Resilience in the Face of Advanced Cancer

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Dedication

This dissertation is dedicated to all the fathers who so willingly gave of their precious time; openly sharing their joys, sorrows, hopes and fears. What a tremendous gift you have given. I will always hold a special place in my heart for each of you.

I wish you and your families peace and strength.

Abstract

This study describes the experiences of 11 fathers living with advanced cancer while raising minor children. Approximately 24 percent of adults living with cancer are parents to one or more minor children equating to approximately 1.58 million parents and 2.85 million children facing this life threatening disease. The literature examining the experience of parents diagnosed with cancer while raising young children has grown over the last two decades. Yet little attention has been paid to parents living with *advanced* cancer moreover the voice of fathers from this body of work is nearly absent. The purpose of this study was to examine how men diagnosed with advanced cancer understand and navigate their role as a father of minor children. Guided by the principles of qualitative research and grounded theory, I developed a theory of resilience based on the stories of these fathers.

Semi-structured face-to-face interviews were conducted with 11 fathers diagnosed with advanced cancer and currently raising children under the age of 18 years old. The interviews were recorded, transcribed verbatim and analyzed using a constructivist grounded theory methodology.

Throughout the interviews fathers described the challenge of “teeter-tottering” between hope and despair. Their desire and eventual ability to live in a place of hope exemplifies resilience. This model identifies the variables that are a part of fathering through advanced cancer and provides a framework for understanding the dynamic and complex process of resilience experienced by these participants. Primary barriers to resilience identified included: level of impairment, uncertainty and financial burdens.

Primary protective strategies included: role flexibility, communication, appraisal-focused skills, utilization of support, and finding meaning.

This study adds to the parental cancer literature by including the experiences of fathers facing advanced cancer. The analysis revealed that when these fathers were diagnosed with advanced cancer their roles changed and the financial pressures mounted. Concerns for their children permeated their cancer experience and influenced their treatment decisions as well as their motivation to survive. Change, uncertainty and loss were woven throughout their experiences as these fathers teeter-tottered between hope and despair striving to live and parent in that place of hope. Understanding both the risk and protective factors that shaped these participants' resilience can inform the development and implementation of supportive resources for these families as well as guide future research. In addition, this study attempted to fill a void in the literature by including fathers facing cancer currently living in the United States and thus sheds some light on this country's social and institutional policies that may impact a father's resilience.

Table of Contents

ACKNOWLEDGEMENTS	i
DEDICATION	ii
ABSTRACT	iii
TABLE OF CONTENTS.....	v
LIST OF TABLES	viii
LIST OF FIGURES	ix
CHAPTER ONE	
INTRODUCTION.....	1
Statement of the Problem	2
Purpose of the Study	3
Overview of the Approach	4
Overview of the Dissertation.....	5
Definition of Terms.....	6
CHAPTER TWO	
BACKGROUND INFORMATION.....	8
Literature Review	8
CHAPTER THREE	
THEORETICAL PERSPECTIVE	26
Role of Theory	26
Family Resilience Theory	27
Ambiguous Loss Theory	31
Family Systems Illness Model	34
Reflexivity Statement	39
Sensitizing Concepts	44
Research Questions	45

CHAPTER FOUR	
RESEARCH METHODS.....	46
Methodology	46
Design.....	50
Sampling.....	50
Recruitment	51
Informed Consent	53
Sample Description	54
Data Collection Procedure.....	57
Interview Plan.....	58
Field Notes and Memos.....	60
Data Management.....	61
Data Analysis	61
Credibility.....	64
Ethical Considerations.....	65
 CHAPTER FIVE	
FINDINGS	68
Grounded Theory of Resilience Process	69
Finding out	75
First Concern was Family	77
Communicating with Children	79
Treatment Decisions.....	85
Cancers Impact on Fathering.....	88
Impact on the Family.....	90
Role Changes.....	94
Time Spent with Children	106
Dreams for the Future	107
Support	110
Finding Meaning	131

CHAPTER SIX	
DISCUSSION AND IMPLICATIONS	137
Barriers.....	138
Protective Factors.....	146
Limitations	162
Implications.....	164
Conclusion	172
References.....	173
List of Appendices	185
Appendix A: Consent Form	185
Appendix B: Initial Codes.....	188
Appendix C: Interview Guide	190
Appendix D: Resource List.....	191
Appendix E: Recruitment Flyer	195

List of Tables

Table 1. Time Phases of Illness Developmental Challenges	36
Table 2. The Stages of the Family Life Cycle.....	37
Table 3. Erikson’s Stages of Individual Development.....	38

List of Figures

Figure 1. Resilience Process of Fathers Living and Parenting With Advanced Cancer	71
Figure 2. The Weight of Uncertainty in the Resilience Process	79
Figure 3. Honest Communication as a Counterbalance in the Resilience Process	85
Figure 4. The Influence of Fatherhood on the Disease Experience	88
Figure 5. Higher Levels of Impairment as Barriers to the Resilience Process.....	94
Figure 6. The Weight of Financial Burdens in the Resilience Process	102
Figure 7. Protective Factors as a Counterbalance in the Resilience Process	109

CHAPTER ONE

Introduction

Cancer is the leading cause of death around the globe and is poised to overtake heart disease to become the leading cause of death in the United States (American Cancer Society, 2010). According to the American Cancer Society (ACS) one in three women and one in two men will develop cancer during their lifetime (ACS, 2010). Despite great advancement in cancer care over the decades, cancer is still one of the most feared diseases and frequently equated with death across cultures (Lagnado, 2008). Currently in the United States there are more than 13 million individuals living with cancer (Siegel, et al., 2012). A recent population-based study fills a critical gap in the literature revealing that approximately 18 percent of newly diagnosed cancer patients are parents to one or more minor children (Weaver et al., 2010). This means that nearly 1.58 million parents must face this life threatening disease while raising their children directly impacting 2.85 million children in the United States (Weaver et. al., 2010). Despite these large numbers of families living with a parent's cancer diagnosis, we are only beginning to uncover how this disease impacts a family's functioning especially when the cancer patient is the father.

It is commonly accepted that cancer is a family disease. When a parent raising minor children is diagnosed with cancer it has a profound impact on the entire family. Facing a parental cancer diagnosis and the weeks, months, or years of treatment under the shadow of extreme uncertainty and pervasive fear of death results in a fundamental shift

in the way the entire family proceeds through life. When a parent with young children is diagnosed with cancer they are often flooded with concern for their children. How will this disease impact my ability to care for my children? How will I talk to my children about my cancer? These concerns can shape their decisions about treatment and impact their ability to recover (Institute of Medicine, 2007). Despite the extreme challenges inherent in living with cancer, parents manage to care for their children (Brenner & Wrubel, 1998).

There is a growing body of literature describing the impact of cancer on parenthood. These studies focus heavily on the mother's cancer experience with insufficient attention paid to fathers facing cancer (Helseth & Ulfsaet, 2004; O'Neill, McCaughan, Semple & Ryan, 2013; Semple & McCance, 2010). We know very little about what it means to be a father with cancer and as a result know even less about how to support these fathers and their families. The main purpose of this study is to advance our knowledge of how a parental cancer diagnosis affects the family's functioning by specifically examining the parenting experiences of fathers living with advanced cancer while parenting young children¹.

The information gleaned through this study addresses two critical gaps in the existing literature by including the father's perspective and examining the extreme challenges of living with advanced cancer. This perspective can be used to inform the development of high quality psychosocial support services for parents with cancer and their families.

¹ For the purposes of this paper the term *young children* refers to children aged 18 and younger.

Statement of the Problem

Substantial advances have been made in the prevention, diagnosis and treatment of cancer over the last several years. As a result, more and more people are living longer even with advanced cancer diagnoses. The relative 5-year survival rates exceed 60 percent for the majority of cancers effecting adults in the 20-49 age group which are prime parenting years (National Cancer Institute, 2009). Thus more and more families are living longer with their cancer often managing their diagnosis like a chronic disease (IOM, 2007). Additionally, these medical advances have led to a shift in cancer care practices from inpatient to ambulatory settings (IOM, 2004) decreasing the time that families have to establish relationships with their care providers (Elmberger, 2002).

Unfortunately, these changes in biomedical care have out-paced advances in the creation and implementation of high quality psychosocial care (IOM, 2007). These changes have critical implications for the well-being of families with young children facing a father's cancer diagnosis especially when the father is living with advanced disease. When cancer has spread beyond the primary site it is generally more challenging to treat and the prognosis becomes more serious often lengthening the period of treatment (IOM, 2007). This protracted disease course also leads to an extension of the myriad challenges facing these families such as the financial costs, caretaking responsibilities, family disruption, role changes and facing an uncertain future (Rose et al., 2009).

All of these challenges and consequences place the family (both as a whole and as individual members) at risk for a broad range of psychosocial problems such as increased levels of depression and anxiety (IOM, 2007). Untreated, these psychosocial problems

can have physical consequences which may influence the course of the cancer. For example, interfering with the patient's ability to adhere to their necessary treatments or effect the functioning of the body's immune system (IOM, 2007). How a family interacts can impact the way parents living with cancer respond to all of these challenges. As Patenaude (2000) states this interaction is a two-way street. Children's wellbeing influences parents just as parent's wellbeing influences their children. (Patenaude, 2000). Understanding how each member of the family experiences the parental cancer diagnosis is crucial to informing the development of effective interventions that consider the whole family.

Statement of Purpose

The purpose of this study is to qualitatively examine how men diagnosed with advanced cancer understand and navigate their role as a father of dependent children with the goal of developing a theory explaining the resilience process of fathers living and parenting with advanced cancer.

Overview of Approach

Using an exploratory design and grounded theory methods, I completed a qualitative study addressing the research questions. I conducted in-person interviews with 11 men who were living with a diagnosis of advanced cancer while parenting children in order to gain their perspectives on the experience. Over the course of the interviews, I began to hear themes of resilience in their stories. As I analyzed the interviews I began to discern specific factors that seemed to positively alter the negative effects of the disease on the participants' ability to live and parent and thus have a protective effect against

feelings of despair and hopelessness. As these participants shared their stories, it became evident the demands of the disease as well as the accompanying treatments created extreme hardships that erected barriers to their sense of hopefulness. Each father's experience was shaped by his ability to balance the protective factors with the barriers in a way that tipped the balance toward hope. This paper describes the experiences of these 11 fathers. Guided by the principles of qualitative research and grounded theory, I developed a theory of resilience based on the stories of these fathers.

Overview of Dissertation

In Chapter two, I present background information and discuss the current literature examining the experience of parental cancer. In Chapter three I present the relevant theoretical perspectives that helped shape my research design and questions. In this current study I applied grounded theory methodology in order to yield a grounded theory that offers an explanation of the experience of fathers parenting through their own advanced cancer diagnosis. While a theoretical perspective is offered, the foundations of my theory were not predetermined by these theories. However, the theories presented did help inform the initial interview questions as described in the third chapter.

The fourth chapter details the research methods used in this study. I describe the sampling, data collection, data analysis process and provide a description of how the grounded theory methods used throughout this process. The fifth chapter details the findings of the study beginning with a presentation of the grounded theory. In chapter six, I discuss my findings in relation to the existing literature to examine convergence and

divergence as well as how these findings can be used to inform social work practice, research and policy.

Definition of Terms

This section provides definitions of the terms that are used throughout this paper².

Advanced cancer: Typically this type of cancer is not contained in the original site and has spread to other parts of the body. Usually this type of cancer cannot be cured or controlled with treatment.

Chemotherapy: A treatment that uses various drugs that are designed to destroy cancer cells.

Chronic Disease: When a disease is persists for at least three months or more or progresses over a period of time.

Colon Cancer: Cancer in the tissues of the colon.

Glioblastoma: In the case of the participants in this study, this is a fast-growing type of cancer that affects the central nervous system and is present in the brain.

Metastasize or metastatic disease: When cancer spreads beyond the primary site to other parts of the body.

Multiple Myeloma: A type of cancer that originates in the white blood cells that produce antibodies.

² All definitions are from the National Cancer Institute Dictionary of Cancer Terms accessed online at <http://www.cancer.gov/dictionary>

non- Hodgkin Lymphoma: There are a number of types of non-Hodgkin lymphoma which is cancer of a type of white blood cell known as a lymphocyte.

Pancreatic Cancer: Cancer of the pancreas.

Prognosis: The expected outcome or course of the disease and the likelihood for the disease to be cured or recur.

Radiation: The use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumors.

Recurrent disease: Cancer that has returned in the body after being undetectable for a period of time.

Remission: When signs and symptoms of the cancer are not readily apparent in the body. However, it is possible the cancer is still present even though it is undetectable.

Soft tissue Sarcoma: In the present study this is a cancer that originated in the muscle.

Watchful Waiting: The process of closely observing the body for signs that there are changes in the cancer. Though treatment is not being offered typically a patient may undergo numerous test and medical exams.

CHAPTER TWO

Background Information

Literature Review

Research on the impact of parental cancer on families is a relatively recent field of study. Beginning in the early 1980's, these studies have continued to expand with much of the research occurring in the last decade (Semple and McCance, 2010). The majority of the studies examining the impact of a parental cancer diagnosis on families with young children are focused on mothers with cancer (Helseth, & Ulfsaet, 2005) and the psychosocial adjustment of their children. In a recent review of the literature, Semple and McCance (2010) identified only one study that centered on the experience of fathers. In order to develop a more comprehensive picture of and provide context to the father's experience parenting young children, I have extended my review of the literature to include the research on children and mothers.

In this review I explore the extant literature examining the impact of parental cancer on the family through studies that focus on how this disease influences the functioning of the individual family members beginning with the children, followed by the parents. Understanding the nature, severity, and prevalence of the psychosocial challenges experienced in these families by each family member is important to inform the need for and design of potential interventions (Osborn, 2007). In addition, I will

discuss demographic factors, family variables, and the characteristics of the parent's disease and how variations in these factors influence a families functioning.

These findings can contribute to a better understanding of which variables associated with this disease experience are the most salient in describing the father's psychosocial functioning within the context of his family. Given its recent history, there are numerous limitations and gaps in the current body of literature examining the impact of parental cancer. These limitations and gaps will be discussed.

Before exploring the literature on the impact of parental cancer on families it is useful to have an overview of the predominant theories and methodologies that undergird the research. The central focus on psychosocial functioning of children is likely influenced by two theories that have informed much of the literature on parental cancer and its impact on the family: family systems theory and theories on stress and coping. The concept that children might be influenced by their parent's cancer and thus their experience investigated is based on family systems theory. Family systems theory asserts that the entire family is affected when an individual member of the family experiences a stressful event (Dubois & Miley, 1999). Ideally, a family has the organizational patterns and communication processes necessary to respond and adapt to a stressor such as parental cancer (Walsh, 2006).

A basic premise of stress and coping theories is that stress and coping are reciprocals of each other, as a result the way people cope with stress is crucial to their physical, psychological and social functioning. Thus ineffective coping strategies can

lead to an increase in stress levels resulting in physical and psychological distress as well as impaired social functioning (Lazarus, 2000).

Much of the research on families living with a parental cancer diagnosis expands on the appraisal models of individual responses to stress, such as Lazarus', to consider the interpersonal aspects and developmental processes associated with stress (Compas et al., 1994).

Measures. The number of studies examining the impact of parental cancer on a family has grown in the last several years. When examining the experience from the perspective of the parent, the vast majority of these use qualitative methods and a cross-sectional design typically relying on in-person in-depth interviews of either one or both parents (Semple, & McCance, 2010). In total these qualitative studies have served to broaden our understanding of the impact of parental cancer on the family functioning by allowing researchers to gain a better understanding of these family members perceived experience. Conversely, the majority of studies investigating the parental cancer experience from the child's perspective have employed a quantitative design.

Findings. Research has substantiated that a cancer diagnosis impacts the whole family (Faulkner and Davey, 2002; Lewis, 1990; Veach and Nicholas, 1998; Welsch, Wadsworth, and Compas, 1996). To date, the vast majority of the studies examine the impact of parental cancer on families by exploring both the children's and parent's wellbeing in terms of their psychosocial functioning. A parent's or a child's psychosocial adjustment to parental cancer can be assessed in a variety of ways. The most commonly evaluated characteristics of psychosocial functioning are internalizing problems including

anxiety, depression, and coping or stress response symptoms and externalizing problems such as aggression or social competence and in addition for children specifically, academic achievement and delinquency.

Research has shown that confusion over a cancer diagnosis, the added anticipation of treatment, and fear of potential death can result in feelings of anxiety, and helplessness for both parents and their children (Compas, B. et al., 1994, Davey, M., Asker, J., and Godette, K., 2003, Grant and Compas, 1995, and Welsch et al., 1996). To date the findings suggest there is variation in family member's psychosocial adjustment to parental cancer that is associated with demographic factors, certain family variables, and characteristics of the disease.

Demographic Factors.

Age of the child & gender of child and parent. The most commonly examined demographic characteristics are the child's age, the child's gender, and the gender of the parent. Currently in the literature children's age has typically been examined by grouping them into separate categories related to their developmental stages: preadolescent/latency, adolescent, and young adult. Overall, the child centered research seems to suggest that adolescents are more vulnerable to higher levels of anxiety, depression, and impaired social functioning than their younger counterparts (Compas et al, 1994; Compas et al., 1996; Welch et al., 1996; Davey et al., 2003; Veach and Nichols, 1998). In one of the most frequently cited investigations of child adjustment to parental cancer, Compas et al.(1996) found age to be the strongest predictor of distress with adolescents reporting more symptoms of anxiety and depression. Adolescence is characterized by numerous

developmental tasks and transitions most prominently separating from their family and aligning more closely with their peers as they strive to develop their autonomy and further define their identity. It has been suggested that this cohort may be more susceptible to psychosocial distress as the demands associated with the disease require them to take on more family responsibilities and assume more caretaking roles (Compas et al., 1994; Grant & Compas, 1995; Veach and Nichols, 1998).

There is no consensus in the findings regarding the impact of gender of the parent or the child on a family's adjustment to parental cancer. The results are somewhat mixed and indicate that when the gender of the child matches the gender of the parent the impact is more significant. For example daughters whose mothers have cancer have been found to experience higher levels of distress than their sons (Compas et al., 1994; Grant & Compas 1994; Welch et al., 1996). However, more recent research by Vannatta et al. (2008) suggests that the impact of maternal breast cancer on the peer interactions of adolescent boys is greater than that of their female counterparts. The differing study designs and samples contribute to the inconsistent findings making it difficult to draw conclusions about the role gender plays when considering the impact of parental cancer on a family at this time.

Level of income & education. While most research examining the impact of parental cancer on the family has included level of income and level of education of the parents, to date, no associations have been reported. It is possible that there is no correlation between these socioeconomic factors and distress levels in families who have a parent with cancer. Given that approximately forty percent of all cancer patients fall

below the federal poverty level during treatment (Yabroff et al., 2004) it would seem that a family's income level would have some relationship to the level of distress experienced by the children and/or their parents. This lack of association may be in part due to the cross-sectional designs utilized in most studies. This type of design may not adequately measure the depletion of a family's financial reserves that often occurs over the course of the disease experience. The lack of association may also be due to heavy reliance on middle and upper class families in the majority of the samples in the current literature.

Family Variables.

Parents' response to the disease. While overall many families appear to eventually adapt quite successfully to their parent's disease, their successful adjustment has been directly linked to the adaptability of the parent (Howes et al., 1994). The literature does seem to suggest that how the parents respond to the cancer contributes to the distress levels of their children. In other words, children function better when their parents cope effectively with the disease (Harris and Zakowski, 2003; Hope and Hodge, 2006; Lewis et al., 1993;). The reverse also appears to be true. Several studies have reported that a parent's number one concern upon receiving their diagnosis was for the well-being of their children (Hymovich, 1993; Semple & McCance, 2010). Participants in a recent qualitative investigation of parents living with cancer reported that the parents were affected by their children's expression of joy (Helseth and Ulfsaet, 2005). Other studies have reported a relationship between a parent's level of distress and their children's distress. For example, parents who self-report higher levels of anxiety or depression report more impaired psychosocial functioning in their children (Kalter, 2002;

Lewis, 2003). Interestingly, it was not uncommon for the parent reports and child self-reports regarding the child's psychosocial functioning to be incompatible. Several studies have reported discrepancies between the parents' perception of the level of distress their children were experiencing and what the children themselves reported (Kalter, 2002; Lewis, 2003; Rosenheim and Reicher, 1986; Welch, 1996).

Changes in roles. Change is an inevitable part of living with cancer and families must navigate numerous changes as a result of a parental cancer diagnosis. Two of the more prominent aspects of change that appear in the literature are changes in the roles family members play and changes to the family routine. Role changes impact both children and parents. Role changes for the parents have been reported by both mothers and fathers prompted primarily because of a decline in their level of functioning that can include physical, cognitive or psychological impairment. In general parents with cancer report not being able to physically care for their children due to side effects from the treatment and needing to rely on help from others (Davey, Askew, & Godette, 2003; Helseth & Ulfsaet, 2004; Semple & McCance, 2010;). Fathers' with cancer reported the key role change as one of moving from primary financial provider challenging their self-image as a working father (Elmberger, Bolland, & Lutzen, 2002). Mother's with cancer have reported similar changes in their roles as providers and caretakers (Fitch, Bunston, & Elliot, 1999; Walsh, Manuel, & Avis, 2005).

Several studies reveal that adolescents in these families have to take on additional caretaking roles previously held by the parent (Ashurst, K, 2007; Davey, Askew, & Godette, 2003; Semple & McCance, 2010). Welsch and colleagues posit these shifts in

roles may place a heavier burden on female adolescents contributing to findings that suggest these daughters of cancer patients experience greater distress than adolescent sons (1996).

Not all changes were experienced as negative. There is evidence in the literature that some perceive their family as stronger and more cohesive as a result of the cancer experience. In the study of fathers by Elmberger and colleagues (2002) men found they were able to have more of a presence in the day to day lives of their children as a result of not being able to work. Other parents have reported a shift in priorities that places being with their children at a higher premium than being at work (Helseth & Ulfsaet, 2004).

Communication. A family's communication patterns regarding the parent's diagnosis and prognosis appears to impact the psychosocial functioning of the family. In general open, honest, and accurate communication about the disease between the parents and their children is associated with better overall outcomes in the family. Qualitative investigations into communication processes may help explain quantitative findings that adolescents are more vulnerable to negative outcomes than younger children in the face of a parental cancer experience. Though one study reported that parents tend to provide more information to adolescents (Barnes et al., 2002) adolescents themselves frequently expressed concern that parents were withholding information (Ashurst, 2007; Kennedy and Lloyd-Williams, 2009). The reason parents withhold information frequently centers on their desire to protect their children and not knowing what to say (Hymovich, 1993; Kennedy and Lloyd-Williams, 2009; MacPherson, 2005).

The uncertainty and anxiety parents experience when speaking with their children about the cancer may impact the quality of the communication. In their quantitative cross-sectional analysis of family functioning in families facing parental cancer, Edwards and Clark (2004), found communication to be the only family functioning variable to have a significant fixed coefficient, with ambiguous communication related to higher anxiety levels. Nelson and colleagues (1994) found higher anxiety levels in adolescents who have a parent with cancer when they felt unable to discuss the disease with their parents. Poor quality of communication has been found to leave children feeling confused (Barnes, 2000; Shands, Lewis, and Zahlis, 2000) and more anxious especially when discussing a parent's terminal illness (Kennedy & Lloyd-Williams, 2009). In Rosenheim's and Reicher's (1985) study of children with terminally ill parents, the anxiety levels of children who had been told the diagnosis by their parents were lower than those of children who were not informed.

Research from the parent's perspectives consistently show that deciding how and what to tell their children about their cancer diagnosis, prognosis and treatment cause them distress (Barnes, Kroll, Burke, Lee, et al., 2000; Helseth & Ulfsest, 2005; Kennedy & Lloyd-Williams, 2009; Kirsch, Brandt, & Lewis, 2003; Stiffler, Haase, Hosei, & Barada, 2008). Often the barrier to quality communication is the parent's desire to protect their children (Barnes, Kroll, Burke, Lee, et al., 2000; Helseth & Ulfsest, 2005). The desire to protect seems to flow the other direction as well according to findings from Kennedy and Lloyd-Williams (2009). In this study the adolescents reported not openly expressing their concerns to the parents in order to avoid upsetting their parents.

Disease Characteristics.

Prognosis. When an individual is diagnosed with cancer understanding the nature of their diagnosis is critical. Beyond defining the type of cancer, patients learn the stage of the disease as well as their prognosis, or the likelihood that they will recover or experience a recurrence. The staging of the disease refers to the severity of the original tumor and the extent to which it is contained at the original site in the patient's body. The stages range in severity from 0 (very early disease that is contained within the layers of cells at the original site) to 4 (the cancer has spread beyond the original site to another organ) (NCI FactSheet, 2009). Throughout the literature on parental cancer a patient's prognosis was uniformly described in terms of the projected 5-year survival rate derived from the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program (NCI, SEER, 2009). It is important to note that 5-year survival rates do not necessarily denote that the patient does not have cancer or is cured but merely reflect that the patient is still alive 5 years past diagnosis.

It is difficult to draw a conclusion about how the variations in a parent's disease impact the psychosocial outcomes of the family. The majority of the literature examining the impact of parental cancer primarily focuses on those families facing a newly diagnosed (within a few months) early stage (stage 1 or 2) disease with a positive prognosis and focuses primarily on the children's perspectives. For example, one quantitative study that did include parent's living with advanced cancer found no relationship between adolescent outcomes and variations in the parent's disease. However, the respondents who had experienced advanced parental disease comprised less

than 10 percent of a very small sample (total n=27 adolescents) (Harris and Zakowski, 2003). Similar results were found by Hoke (2001) in her study comparing the psychosocial adjustment of children of mothers with breast cancer to a comparison group of children whose mothers had benign biopsies. Only seven percent of the sample was living with stage 3 or stage 4 diagnoses and no respondents reported experiencing a recurrence. The findings are further limited by the response rate: nearly one-half of the adolescents in the study did not complete their portion of the Child Behavior Check List (CBCL) (Achenbach, McConaughy, & Howell, 1987).

Studies that have included a broader range of disease characteristics seem to indicate that a poorer prognosis is associated with more negative self-reported outcomes amongst children and adolescents (Compas et al, 1994 and 1996). A child's wellbeing seems to be impacted by the way the child perceives the parent's disease. A child's anxiety and depression increase when they define their parent's disease as serious (Compas et al., 1996). This finding is consistent with an earlier study that also indicates that a child's level of anxiety and depression increases as in accordance with the seriousness of the parent's cancer diagnosis (Siegel et al., 1992).

While the studies examining recurrent parental disease are limited in number they seem to indicate that family functioning is negatively impacted by the return of the cancer. One study in the Netherlands found that both boys and girls between the ages of 11 and 18 years old reported significantly higher levels of total problems and total distress respectively than did the comparison cohort (Huizinga et al., 2005). A more recent study examining the temperament of Dutch adolescents who have a parent with

cancer found higher levels of fear and worry in adolescents whose parent had experienced a recurrence compared with those whose parents had not (Visser, et al., 2007). This is consistent with findings indicating a lower overall quality of life for women living with recurrent breast cancer and was associated with more negative mental health outcomes for their family members (Northouse et al., 2002).

Very few studies have examined the experience of parenting through cancer from the perspective of families living with advanced parental disease. I was unable to identify any studies that examined the experience of parenting through recurrent or advanced disease from the parent's perspective – a critical gap. To date the literature examining childhood bereavement offers the most insight into the full force of advanced parental disease. One seminal study found terminally ill cancer patients and their children to be very isolated and experiencing high levels of anxiety (Rosenheim and Reicher, 1986). The authors noted that “children and parents in anticipatory grief do not receive a normative perspective to perplexing feelings and alternatives of action similar to those offered in actual mourning” (p. 119).

Seigel et al. (1992) reported similar findings. In this study children between the ages of seven and sixteen who had a parent die within six months of the initial interview were compared with a community sample. The self-reported levels of anxiety and depression in the study group were significantly higher. In addition, the parent's reported significantly higher scores on total behavior problems and levels of anxiety and depression and lower levels of social competence in their children. It is interesting to note that Seigel and colleagues reported consensus between the parents' reports on the CBCL

and the children's' self-reports. This was not the case with the Rosenheim and Reicher (1986) study which found that the parents were less reliable judges of their children's maladjustment.

These more negative outcomes may be associated with the length of the disease, with longer disease experiences being associated with more distress in families (Dunning, 2006; Salinger, Porterfield, and Cain, 2004). Salinger and colleagues (2004) found a significant negative correlation between the length of disease and parenting quality and suggest that this is due to the cumulative strains and losses experienced in the family due to a parent's terminal disease.

The above findings indicating higher levels of distress in families facing recurrent and advanced parental cancer, though limited in number, also align with my practice experience. In my position as director of a program that educates and supports families facing parental cancer, I have witnessed time and again as families experiencing recurrent and advanced disease become increasingly anxious by the ambiguity of their prognosis, the accumulating strains and the layers of loss experienced. This heightened distress has at times left family members floundering for direction leading to increased levels of anxiety and depression among other various negative outcomes. Gaining a clearer understanding of how advanced parental disease impacts the entire family is critical to the design of effective interventions.

Intervention Studies. Like other areas of the parental cancer literature, studies examining the effectiveness of interventions are relatively limited. The few studies on intervention tend to be small but some themes are emerging. In one study of children in

families that participated in family-centered counseling had lower levels of anxiety than the children of families who didn't participate in the intervention (Rosenheim and Reicher, 1986). Other studies indicate programs that focus on including the entire family and strive to improve family communication patterns seem to be effective in reducing the levels of distress for the entire family (Greening, 1992; Hoke, 1997; Swick, and Rauch, 2006; Taylor-Brown, Acheson, and Farber, 1993; Walsh-Burke, K., 1992). Overall, these studies tend to focus on peer support interventions which are developed for white, middleclass, women (Semple & McCance, 2010). Intervention research is needed that includes a broader socioeconomic class, more ethnically diverse families (IOM, 2007) and takes the needs of men into consideration.

Limitations and gaps in the literature. As noted above there are numerous gaps in this area of study. These gaps occur primarily in the methods employed including the overall study designs and the sample characteristics.

Methods. One primary limitation in the research examining the impact of parental cancer on the family is in the choice of epistemological standpoints and measurement tools. Currently, no instrument exists to specifically measure the psychosocial functioning of children or their parents when a parent is diagnosed with cancer (Visser, A. et al, 2004). In order to measure the various characteristics of a child's psychosocial adjustment to parental cancer the majority of quantitative studies utilize the following instruments: Child Behavior Checklist (CBCL), the Youth Self Report, the Children's Depression Inventory (CDI), and/or the Revised Children's Manifest Anxiety Scale (RCMAS). The CBCL assesses the child's behavioral, emotional and social functioning

as reported by their parent(s). Consisting of 120 problem items, the CBCL offers three response options for each item including: 0 = not true, 1 = somewhat or sometimes true, and 2 = very true or often true (Achenbach, 1987). Recent studies have confirmed the cross-cultural validity for the CBCL (Ivanova et al., 2007, and Leung et al., 2005).

The inclusion of these standardized scales represents an area of potential limitation in these studies. Though these scales have been used in the medical setting and are well-established standardized measures of child psychosocial functioning, previous research has indicated that standardized scales such as the CBCL, and YSR, may lack the required level of sensitivity to accurately measure more subtle changes in a child's level of distress as it is related to parental cancer (Compas et al., 1996; Lewis, 2007). In other words, results showing an absence of a negative outcome do not necessarily indicate positive well-being. Nor are they able to assess a child's level of concern or communication patterns within a family (Hoke, 2001). Despite these limitations, the CBCL is one of the more widely utilized instruments in assessing child well-being when the parent has cancer.

While the majority of the studies examining the impact of parental cancer from the parent's perspective have been qualitative, this is not the case for investigations from the child's perspective. This over-reliance on quantitative methods when measuring the impact of parental cancer on children may reduce this experience to pre-formulated responses that include concepts that may not be familiar to every family member, especially children (Lewis, 2007). For example, in more than one study a substantial number of pre-adolescent children (more than one-third) scored above the 90th percentile

on the lie factor of the R-CMAS which may have influenced their lower scores on this scale (Compas et al., 1994; Kalter et al., 2002). While quantitative designs using measures that have been determined to be both reliable and valid are important, they may not be sensitive enough to assess more subtle changes in psychosocial adjustment (Christ et al., 2006).

Sample. The samples included in the investigation of the impact of parental cancer represent its greatest limitation both in terms of the socio-demographic characteristics and in terms of disease characteristics. In general the samples were drawn from predominantly Caucasian, middle and upper class, educated, two-parent families. Few studies include representation from families who are traditionally underserved: single parent families, same-sex parent families, and those families of color or of low socio-economic status. This is a serious gap in the literature as individuals from these traditionally underserved groups are consistently diagnosed with later stage diseases and thus have more challenging cancer experiences than their Caucasian counterparts (Ward et al, 2004).

Samples were also limited by their near exclusion of families living with more challenging diagnoses such as recurrent disease or an advanced and potentially terminal cancer diagnosis. The more recent study examining temperament of Dutch adolescents who have a parent with cancer found higher levels of distress in adolescents whose parent had experienced a recurrence compared with those whose parents had not (Visser, A. et al., 2007). Unfortunately, there are no other studies to confirm or contradict these findings.

Finally there is an enormous gap when it comes to gender. As noted above, recent reviews of literature examining the parent's experience specifically found few studies that included a father's perspective and only one study that focused specifically on the experience of fathers (O'Neill, McCaughan, Semple & Ryan, 2013; Semple & McCance, 2010). The majority of research examining the impact of parental cancer from a parent's perspective relies heavily on the mother's experience, particularly Caucasian mothers with breast cancer. As Semple and McCance (2010) observe, "It cannot be assumed that the experience of parenting following a diagnosis of breast cancer is similar to, for example, a father with head and neck cancer" (p.117).

This is a serious gap given the changing nature of fatherhood in the United States and important role fathers play in their child's development. The familial role men play as fathers has been evolving in recent decades. Cabrera and colleagues (2000) suggest men are no longer viewed simply as the financial breadwinner but are seen as taking on additional roles in American families becoming more involved in child-rearing activities. Moreover, research indicates that fathers have a unique contribution to make to in their child's developmental outcomes. A review of the literature examining the effects of father involvement on their children's development found a positive relationship between levels of engagement by fathers across social, behavioral, psychological and cognitive outcomes for their children (Sarkadi, Kristiansson, Oberklaid and Bremberg, 2008).

The gaps mentioned above not only exist in the research arena but ripple into the practice arena as well. There are very few programs around the country that address the specific needs of families in which a parent has cancer and is actively raising minor

children. Too often the programs address the needs of the parent living with cancer independent of the needs of their family, focus primarily on the majority culture, and are rarely offered in languages other than English. For the few programs that do work with the children of these parents, very few include the parents in their groups.

Family members as well as the professionals supporting them are confronted with several important questions. Chief among them is how to determine whether any intervention is necessary and if so, what type of intervention would be the most appropriate. Gaining a clearer understanding of the impact of an advanced diagnosis on the father of young children is a critical piece of this puzzle.

CHAPTER 3

Theoretical Perspective

The role of theory

Grounded theory methodology as originally conceived by Glaser and Strauss (1967) emphasized the importance of delaying a literature review including a detailed examination of theory in order to ascertain that the theory derived at from the investigation was truly inductive. Over time there has been some disagreement on this stance and there is acknowledgement that a theoretical perspective can be appropriate (Corbin & Strauss, 2008). Corbin and Strauss along with others caution that researchers must “remain open” to new ideas and concepts as they emerge from the data (Charmaz, 2006; Daly, 2007; Oktay, 2012). Charmaz (2006) citing Strauss and Corbin noted that as researchers we come to our work with knowledge gained through professional experience and the literature in our field. As a practitioner who has been working with families facing parental cancer for nearly two decades, I have use theory to inform my work. Thus it is impossible for me to come to this research without a theoretical perspective. This section details three perspectives that have shaped my practice over the years and as such helped shape this study primarily by influencing the sensitizing codes as well as the initial interview questions. These three perspectives are, Family Resilience Theory, Ambiguous Loss Theory, and the Family Systems Illness Model. I complete this

discussion with a reflexivity statement, a description of the sensitizing concepts used in this study as well as my specific research questions.

Family Resilience Theory

As mentioned above the predominant theories employed to examine the impact of parental cancer on families are stress and coping theories and family systems theory. Little to no research has utilized a strengths-based perspective when examining the impact of parental cancer. The research emphasis has been on negative outcomes often equating a cancer experience to a pathological process (Lewis, 2007). As a result, very little attention has been given to families who have demonstrated resiliency in the face of this disease.

Definitions of resilience have evolved over the last several decades. The conceptualization of resilience emerged out of the field of developmental psychopathology and specifically research examining children's ability to adapt to early life stressors (Wright & Masten, 2013). Resilience is generally defined as the ability to rebound from difficulty or hardship (Fernandez, Schwartz, Chun, & Dickson, 2013). Initial investigations posited that various protective and risk factors could alter the effects of adversity over time (Garmezy, 1993; Masten, Best & Garmezy, 1990). For example, Garmezy (1993) described personality traits such as reflectiveness, a cohesive family structure and positive social support as contributing to resilience in children. Risk factors such as chronic poverty or pessimistic personality traits were suggested to increase vulnerability and interfere with a child's resilience. The families in which those children lived also contributed to their resilience both in terms of supporting adaptation and

growth in the face of stressors and as the source of that distress (Garmezy, 1993). Over time resilience was no longer conceived as an individual phenomenon but as a process with a relational component that attended to the family as a unit (Nichols, 2013).

Current theories on family resilience arose out of investigations of families' ability to respond to separation and reunification after World War II which focused on the ability of a family to attenuate the distress caused by the crisis as resilient (Nichols, 2013). Similar to the evolution of work on individual resilience, studies on family resilience shifted from a primarily crisis orientation to understanding the importance of considering both the extent of the crisis and a family's strength and resources (Nichols, 2013).

For example, the McCubbin and Patterson (1983) Family Adaptation and Adjustment Response (FAAR) model describes the pathways toward family adaptation and eventual adjustment as they balance the demands of a stressor such as an illness with the family's resources or capabilities. The model posits that the meaning family members attribute to the crisis can shape the magnitude of the risk and inform the protective capacities of the family. When the nature and magnitude of the crisis exceed the family's ability to respond, the family is at risk of significant disruption and challenging their ability to adapt (Patterson, 2002). This depiction of family resilience as an ongoing process of adaptation in the face of crisis provides a constructive lens through which to examine the impact of parental cancer.

Walsh (2006), a leading scholar on family resilience, also constructed a valuable framework for understanding a family's experience with parental cancer. Walsh (2006)

offers a definition of family resilience that emphasizes resilience as “an active process of endurance, self-righting and growth” (p.4) in the face of family stressors. this relational component. She describes family resilience as the family’s “capacity to rebound from adversity strengthened and more resourceful” (p.4) and specifically emphasizes that “resilience is forged through adversity, not despite it” (p.7). Hartling (2003) enriches our understanding of resilience by defining resilience as “the ability to connect, reconnect, and resist disconnection in response to” adversity (p.3).

Walsh (2006) posited three key components that contribute to family resilience and include, communication processes, organizational patterns, and belief systems. Early evidence garnered from research in this field indicates that the way a family communicates and organizes itself in the face of adversity matters. However, a family’s belief system is yet to be explored. The concept of a belief system describes how a family makes meaning of an experience. These core meanings are constructed by weaving together their larger social world, cultural influences, spiritual beliefs, past family generations, and ideas for the future. A family’s system of belief deeply influences how a family makes sense of a crisis such as a cancer diagnosis. According to Walsh, resilient families are able to make meaning of a crisis that is relationally based, and normalizes the crisis. Furthermore this meaning would create a sense of coherence by providing a context that includes a hopeful interpretation of the adversity.

How a family organizes itself in the face of adversity can influence its ability to be resilient. Effective family organizational patterns provide a safety net around a family and can act as “family shock absorbers” (Walsh, 2006, p.83). The ability of a family to be

flexible in the face of a crisis is critical to resilience. Flexibility allows a family to adapt more fluently to the constant change inherent in a life threatening disease experience. This flexibility might include the adaptation of daily routines or a redefinition of various roles in the family. Walsh emphasizes the relational component in her concept of family organizational patterns that include a connectedness among the individual family members as well as their extended family, community, and larger systems such as the medical institutions on which a family often relies.

Communication that is clear, consistent, and honest contributes greatly to family resilience. Effective communication patterns include the opportunity for family members to openly express a variety of emotions and create a family narrative that each member is a critical piece to managing the crisis (Walsh, 2006). These qualities of communication contribute to resilience by establishing trust between family members. Communicating painful information to children is one of the greatest challenges facing a parent navigating a life-threatening disease. As I have observed and as the research indicates, it is often a desire to protect that inhibits a parent's ability to speak openly and honestly to their children particularly when cancer enters the chronic and terminal stages.

The interface of resilience and cancer has been increasingly explored in the literature investigating cancer survivorship issues. In 2005, a leading journal in the field, *Cancer*, devoted an entire issue to the resilience of people living with cancer. Research is beginning to establish that key components of resilience contribute to an increased quality of life for cancer survivors and their families (Rowland, 2005). However, more

research is needed which explores resiliency in families facing parental cancer while they are parenting young children.

Ambiguous Loss Theory

Being diagnosed with cancer means having to make a fundamental shift in the way a family proceeds through life including adjusting the way they define themselves as individuals and as a family unit, the way they live their daily life and the way they envision their future. Inherent in this cancer experience is ambiguity and loss.

Ambiguity in the cancer experience is best described as lacking clarity or definition. Ambiguity is woven throughout the entire cancer experience from before the point of diagnosis to the completion of treatment and beyond. This is especially true for families with minor children in which a parent is living with a diagnosis of advanced cancer. For these families the ambiguity is most profoundly exemplified in the prognosis. In most cancers once the disease metastasizes in the body, the individual's prognosis for survival declines dramatically and the goals of treatment often change from curative to a focus on containment of the disease. Yet with the sophisticated treatment options currently available there is legitimate reason for a family to hope that this cancer diagnosis can be managed more like a chronic disease until a new treatment regimen arises that may offer a cure (IOM, 2007). As a result, parents living with advanced disease must hold two opposing truths simultaneously. One truth is that they are living with a terminal illness and need to prepare themselves and their family for a potential death. The second truth is that there is legitimate reason to hope for containment of the

disease and even for a cure thus they must prepare their family for living and fighting for a cure.

In my practice as director of a program that educates and supports families facing parental cancer, I have witnessed time and again as families become overwhelmed by the ambiguity of their prognosis. However, I have also witnessed families navigate this ambiguity with amazing alacrity. Consider the following brief case example of a client living with advanced ovarian cancer. One evening at group she reported how she spent the morning hosting a luncheon to which her and her daughter had invited several women from their family and their community. The purpose of the gathering was for these women to offer their commitment to supporting and guiding the daughter as she grew into womanhood should her mother not be around to help accomplish this task. She then spent the afternoon arguing with her oncologist about getting her into a clinical trial and with the airlines about bringing her oxygen tank on the plane for a trip to Italy that next fall. Clearly she was able to both prepare for the potential of her death and still advocate for her future.

The cancer experience can also be characterized by myriad losses that are an inevitable part of life with this disease. Some of these losses are easily recognized such as the loss of a breast or bodily function as a result of the necessary treatment. Other losses are less easily recognized and as a result often not validated by the family members themselves or by the larger community in which they live. For example, consider a family in the midst of raising young children and one parent is diagnosed with cancer. The parent living with cancer must abruptly shift their primary focus from

parenting to their survival. The remaining parent's role also quickly transitions to that of caregiver to the other parent and as a result their focus also shifts and is no longer primarily on their children. As a result children can lose two parents without this loss being noticed since both parents are in fact still physically present. The following brief case example offers one illustration how this loss of parental attention can manifest in a family.

A father busy caring for his wife who had been violently ill all day as a result of her chemotherapy regimen realized when he came to group that night that his nine year old son had only had Cheetos to eat that day. He had forgotten to feed his son and the realization of this fact laden him with a sense of guilt and shame that was palpable. It is important to note that this man was not a neglectful parent. His loss of focus on his child, his son's loss of parental attention was due to an external event that was outside this family's control – cancer.

How do all members of a family from a variety of racial, ethnic and socio-economic populations understand their cancer experience, find meaning in this journey and successfully meet and manage the ambiguity and loss inherent in this disease? I would suggest that ambiguous loss theory provides a useful lens through which to begin to address the above question. Building on family stress theory and resiliency theory, ambiguous loss theory has been constructed over the last several years by Pauline Boss. Boss (2007) defines ambiguous loss as “a loss that remains unclear” (p. 105). A loss is considered unclear or ambiguous if there is lack of definition or clarity about the status of the loved one either physically or psychologically. According to Boss (1999, 2007) there

are two different types of ambiguous loss. One type is characterized by a physical absence and psychological presence of a loved one such as a soldier lost in action. The second type is described as a psychological absence with a physical presence. It is this type of ambiguous loss that applies to families facing cancer as in the case example offered above where both parents were psychologically absent for their child as they were both so focused on the survival of the parent diagnosed with cancer. Boss (1999, 2006, 2007) contends that these ambiguous losses are the most stressful as they are often not validated by the larger community through the application of traditional rituals.

Ambiguous loss is further characterized by its emphasis on the relational aspect as opposed to the individual pathology. As a result using this theory as a guide to examine the meaning of an advanced cancer diagnoses in a family would simultaneously address two gaps in the current research. First, it is not a problem-focused theory but one that emphasizes a focus on family resilience. Boss' theory of ambiguous loss would include a hopeful interpretation of the cancer experience emphasizing the value of finding meaning. Ambiguous loss theory would have as its goal for a family facing cancer to be able to tolerate ambiguity, find meaning in their losses, and even thrive despite the significant amount of stress that accompanies their life circumstance.

Family Systems Illness Model

The Family Systems Illness model (FSI) provides a useful framework for examining how the stage of a disease intersects with the individual and family developmental process leading to distress, disruption and potentially to ambiguous loss. Building on family systems theory in addition to existing individual and family

development theories, John Rolland developed the FSI model which suggests that cancer “be viewed in a developmental context, involving three evolutionary threads: illness, individual, and family development” (Rolland, 2005).

Based on the assumption that illness has distinct phases each with its own developmental tasks, this model postulates that the psychosocial developmental phases of cancer consist of the type of diagnosis, disease course, the prognosis, level of impairment, and the time phases of illness which include crisis, chronic, and terminal (Rolland, 2005). Inherent in each of these time phases are psychosocial developmental tasks that challenge a family in specific ways. The crisis phase is primarily defined by the point just prior to diagnosis and the “initial period of readjustment and treatment” (p. 2587). This stage is followed by the chronic phase which is characterized by a sense of uncertainty and exhaustion where families can feel like they are “living in limbo” (p. 2587). This phase can have episodic components to it often including times when the cancer is in remission or there is no evidence of disease and then times when the disease recurs and/or advances and treatment begins again. The final phase in the model is the terminal phase which is defined as the period when it becomes clear that death is assured and this knowledge permeates a family’s daily life.

Table 1. Time Phases of Illness Developmental Challenges

Crisis phase	Chronic phase	Terminal phase
<ol style="list-style-type: none"> 1. Family members understand themselves in systems terms 2. Gain psychosocial understanding of illness <ol style="list-style-type: none"> a) In practical and emotional terms b) In longitudinal and developmental terms 3. Gain appreciation of developmental perspective (individual, family, illness life cycles) 4. Crisis reorganization 5. Create meaning that promotes family mastery and competence 6. View challenge of illness as a shared one in “We” terms 7. Accept permanence of illness/disability 8. Grieve loss of family identity before chronic disorder 9. Acknowledge possibilities of further loss while sustaining hope 10. Develop flexibility to ongoing psychosocial demands of illness 11. Learn to live with symptoms 12. Adapt to treatments and healthcare settings 13. Establish functional collaborative relationship with healthcare providers 	<ol style="list-style-type: none"> 1. Maximize autonomy for all family members given constraints of illness 2. Balance connectedness and separateness 3. Minimize relationship skews 4. Mindfulness to possible impact on current and future phases of family and individual life cycles 5. Live with anticipatory loss and uncertainty 6. Balance open communication (vs. avoidance, denial) and proactive planning with need to live a “normal” life, keeping threatened loss in perspective 	<ol style="list-style-type: none"> 1. Completing process of anticipatory grief and unresolved family issues 2. Support the terminally-ill member 3. Help survivors and dying member live as fully as possible with time remaining 4. Begin the family reorganization process

·Originally Excerpted from Rolland JS, 2005

In addition to the developmental stages of the disease the FSI model considers the developmental stages of the individual and the family. Rolland (2005) offers Carter and McGoldrick’s description of the phases of the family life cycle as a useful framework to interface with the distinct phases of cancer outlined above while Erik Erickson (1998) captures the individual developmental stages (Tables 1 & 2).

Table 2. The Stages of the Family Life Cycle

Family life cycle stage	Emotional process of transition: key principles	Second-order changes in family status required to proceed developmentally
Leaving home: single young adults	Accepting emotional and financial responsibility for self	a. Differentiation of self in relation to family of origin b. Development of intimate peer relationships c. Establishment of self in respect to work and financial independence
The joining of families through marriage: the new couple Families with young children	Commitment to new system Accepting new members into the system	a. Formation of marital system b. Realignment of relationships with extended families and friends to include spouse a. Adjusting marital system to make space for children b. Joining in child rearing, financial and household tasks c. Realignment of relationships with extended family to include parenting and grand parenting roles
Families with adolescents	Increasing flexibility of family boundaries to permit children's independence and grandparents' frailties	a. Shifting of parent/child relationships to permit adolescent to move into and out of system b. Refocus on midlife marital and career issues c. Beginning shift toward caring for older generation
Family life cycle stage	Emotional process of transition: key principles	Second-order changes in family status required to proceed developmentally
Launching children and moving on	Accepting a multitude of exits from and entries into the family system	a. Renegotiation of marital system as a dyad b. Development of adult-to-adult relationships between grown children and their parents c. Realignment of relationships to include in-laws and grandchildren d. Dealing with disabilities and death of parents (grandparents)
Families in later life	Accepting the shifting generational roles	a. Maintaining own and/or couple functioning and interests in face of physiological decline: exploration of new familial and social role options b. Support for more central role of middle generation c. Making room in the system for the wisdom and experience of the elderly, supporting the older generation without over functioning for them d. Dealing with loss of spouse, siblings, and other peers and preparation for death

a Excerpted from: Carter B, McGoldrick M., 1999.

Table 3. Erikson’s Stages of Individual Development

Individual Life Cycle Stage	Ego Development Outcome	Basic Strength
Infancy: birth to 18 months	trust vs. mistrust	Drive and hope
Early childhood: 18 months to 3 years	Autonomy vs. shame	Self-control, courage, and will
Play age: 3 to 5 years	Initiative vs. guilt	Purpose
School age: 6 to 12 years	Industry vs. inferiority	Method and competence
Adolescence: 12 to 18 years	Identity vs. role confusion	Devotion and fidelity
Young adulthood: 18 to 35	Intimacy and solidarity vs. isolation	Affiliation and love
Middle adulthood: 35 to 55 or 65	Generativity vs. self-absorption or stagnation	Production and care
Late adulthood: 55 or 65 to death	Integrity vs. despair	Wisdom

The FSI model contends that it is critical to understand how these three developmental frameworks interface when working with families facing cancer in any capacity including both micro level (medical/physical and clinical/psychosocial) or macro level (research and policy) settings.

The Intersection of Family Resilience Theory, Ambiguous Loss Theory and Family Systems Illness

Based on many years of my experience as an oncology social worker, extant research, and the assumptions of the FSI model, it appears that it is during cancer’s chronic and terminal phases when a family’s resilience is challenged and they become most at risk of experiencing negative outcomes. The salient question in the clinical application of the FSI model becomes: What happens when a *perfect storm* occurs creating a fundamental collision between the developmental tasks associated with individual and/or family development and the psychosocial tasks associated with living with a chronic or terminal cancer diagnosis? Secondly, what are key components of resilience that serve as protective factors in this situation?

Weaving together the FSI model with ambiguous loss and family resilience theory can guide this investigation toward a clearer understanding of the experience of fathers facing their own advanced cancer while simultaneously dealing with the challenges of parenting young children. How does a father navigate this experience?

My professional and personal experience confirm that cancer can be a relentless and consuming disease that can exhaust even the most intact and resilient families. Fortunately families can and do meet and manage this challenge maintaining or even enhancing their cohesiveness no matter what the outcome. Family resilience theory, ambiguous loss theory and the Family Systems Illness model can guide research in this area toward a deeper understanding of how fathers facing advanced cancer navigate this crisis from a strengths-based perspective. In turn this increased understanding can inform social work practice and research with families facing cancer as well as be used to craft policies that support these families through this life-altering experience.

Reflexivity Statement

Since the researcher is an important data collection instrument in qualitative research using grounded theory methods, it is important to describe how I stand in relationship to the topic (Charmaz, 2006). This reflexivity statement will describe how my assumptions, biases, preconceptions, professional and personal experiences with this topic may have influenced my understanding, observation, and analysis.

Reflexivity and credibility are intertwined. Reflexivity in the qualitative research process enhances credibility by providing clarity about how researchers develop their ideas and shape their findings (Daly, 2007; Gilgun, 2011). Daly (2007) defines reflexivity

as “the ways in which a researcher critically monitors and understands the role of self in the research endeavor” (p.188). Being reflexive means we observe and record how we have influenced the research process including the influence of our physical presence, the influence of our interactions, the influence of our cultural constructions and social positioning, and the influence of our voice. The role reflexivity plays in the research process and how researcher bias is attended to depends greatly on how the researcher positions themselves epistemologically as well on their professional and personal experiences (Charmaz, 2006; Daly, 2007).

Social constructionist perspective. Epistemological reflexivity urges us to carefully consider our assumptions about the world and knowledge in the context of a research study (Daly, 2007). My assumptions about the world and knowledge align most closely with the social constructionist paradigm. That reality can never be truly defined but is a matter of combining perception and understanding of the social world in order to construct a shared meaning. This results in a reality that is perceived in multiple ways (Daly, 2007). I concur with this more subjectivist position and believe that one can never fully remove oneself from the research process. That our experiences, both as professionals and individuals, infuse the entire research process beginning with how we select our topic, our participants, our methodology, the contents or our questions, the interpretation of the data, and finally how the results are written and disseminated (Charmaz, 2006; Daly, 2007; Finlay, 2002). These assumptions influenced my entire research process including how I choose my topic, selected the research participants,

developed the questions, chose and applied the methods as well as how I analyzed and reported the findings and interpreted the implications.

Professional experiences. My own experiences with cancer both professionally and personally inform my beliefs that the impact of this disease extends beyond the person diagnosed to include their family and their larger community. As the director of a program that works with families facing parental cancer, I have walked with families as they have faced the devastating consequences of an advanced cancer diagnosis that stretch beyond the physical pain and disfigurement and include deep emotional, spiritual and financial strains. What constantly amazes me is that so many parents and children get up every day and strive to live fully in the face of these extraordinary challenges. I stand in awe of their perseverance and strength. However, I also experience an inordinate sense of frustration that after all of this time and money there are still not enough quality services and adequate policies in place to begin to meet the needs of these families. I bring to this research a strong sense of social justice. I believe this project can offer valuable insights into these experiences that can inform a theory about those experiences and, in turn, influence the development of appropriate, targeted interventions and policies that alleviate the unnecessary suffering these families endure.

Personal experiences. Given that one in two men and one and three women will be diagnosed with cancer in their lifetime (ACS, 2010), it is not a surprise that I come to this project with personal experiences. I have supported a number of family members and friends as they faced their cancer diagnoses including both my mother-in-law and father-in-law, and three very dear friends. Most challenging has been watching my cousin, who

is like another brother to me, struggle through a difficult cancer experience while raising newborn twins. He was diagnosed more than a decade ago and is still in treatment. Like the many parents I serve, he has to live with debilitating consequences related to the disease and the treatments that impact his ability to eat, sleep, think, work, and to be a father. I believe that had he had better quality biomedical and psychosocial interventions along the way his current suffering would be lessened.

Given my extensive professional experiences with fathers facing advanced cancer, I needed to strive to adopt a position of “not knowing” (Daly, 2007). This did not necessitate that I completely shelve my own ideas but that I “hold them in tension” with my need to remain open to the stories presented (Daly, 2007). I saw my responsibility as the interviewer to create the framework for the interview and then be an attentive listener.

My social location. In addition to my professional and personal experiences, my own social location needed to be considered. My position as a white, middle class, educated person differed from some of the research participants, aligned with others and shaped my understanding of these men’s experiences. I also found it necessary to be aware of how my current status as a parent influenced my understanding of the participants’ stories. Most of the fathers I interviewed had children of similar ages as my own. This was both an asset and a point of caution. At times I easily understood references to some of the joys and challenges that are part of raising children. Yet I tried to be cautious and not assume I fully understood those references and worked to ask clarifying questions.

It is important to note I differed from the participants in two key ways, disease status and gender. First and foremost, I do not have cancer. Though my professional and personal experiences have led to a clear understanding that I could just as easily be sitting on the other side of the table, I recognize that this separates me from their experiences. I did not find this to be a barrier as the fathers in this study appeared to be quite open and honest about their experience. This separation may have allowed the participants to speak more freely as they may not have felt the need to protect me from the hardships associated with their experience. I found this to be true when conducting a needs assessment for women with metastatic breast cancer to design a “buddy” to guide them through their cancer experience. Unanimously the women with metastatic disease voiced concern that they would not be able to fully express themselves to their buddy if they had to worry about that person’s own fears of recurrence.

My gender also separated me from the participants in this study which posed some challenges and interesting advantages. In her interview with divorced fathers Arendell (1996) found that this difference in gender caused discomfort for some participants that appeared to be associated with a concern about their identities as men. Charmaz (2006) pointed out that some men are more comfortable sharing private experiences with a woman. I saw these fathers as the experts on their own lives from whom I could learn. I attempted to communicate that stance from the first point of contact and throughout the research process. While, I overall, I found the participants to be quite open it is possible that our difference in gender caused them to curb their stories

in some way. Communicating that position to the participants seemed to have facilitated an interview relationship that was empowering for the men and mutually respectful.

Sensitizing Concepts

Qualitative researchers do not enter into investigations as completely blank slates but bring with them a sense of theory, extant literature, and other knowledge that form a set of ideas about the topic (Glazer and Strauss, 1967; Charmaz, 2006).

Sensitizing concepts are a way for researchers to use these ideas to orient their initial inquiry (Patton, 2002) and guide their ongoing investigations (Daly, 2007). Charmaz (2006) describes sensitizing concepts as useful throughout the research process. In the data collection and analysis process sensitizing concepts can act as a bridge between interviews helping to organize and describe the data (Patton, 2002).

Sensitizing concepts played an important part in this study. I developed an initial list of codes for this investigation (Appendix B). These initial codes were derived primarily from my professional experience. They were also influenced by my personal experience and my knowledge of the literature and theory. These codes provided a loose frame and served as a springboard for developing further concepts across each level of analysis (Charmaz, 1990, 2006). Data isn't forced to fit the sensitizing concepts but rather sensitizing concepts evolve throughout the research project to better fit the data (Charmaz, 2006).

Summary

Attending to the needs of the parents with cancer and the needs of their children is an extremely challenging but necessary part of cancer care and there are considerable gaps in this research. This study extends previous research on families facing cancer by evaluating the impact of cancer on fathers with young children, diversifying the study population, including advanced diagnoses, and employing qualitative methods. Gaining a better understanding of a father's experience will provide parents and professionals, a greater insight into the strengths and vulnerabilities that shape a father's resilience in the face of this life-threatening disease thereby enabling the design and implementation of interventions that are more inclusive of fathers.

Research Questions

The purpose of this research is to develop a grounded theory that explains how men diagnosed with advanced cancer understand and navigate their role as a father of dependent children. The central questions are: How do fathers living with an advanced cancer diagnosis navigate their role as a father of young children? How do they perceive this experience impacting their individual as well as their family's functioning? How do they interpret the meaning of this experience?

CHAPTER FOUR

Research Methods

Methodology

Given the near absence of existing research into the experience of fathers living with advanced cancer while parenting young children, I chose to do an exploratory study as this type of design is particularly suited to investigations where little is known about the phenomenon (Babbie, 2007). Due to the exploratory nature of this study and the questions proposed a qualitative research design was chosen. The data was collected using in-depth interviews with 11 fathers living with a diagnosis of advanced cancer while parenting minor children. A social constructionist version of grounded theory method guided the data collection and analysis.

The interpretive paradigm associated with qualitative research holds central that reality is socially constructed, influenced by age, gender, race, class, and culture (Grbich, 2007) and that causal connections are subjective and explainable not predictable (Denzin and Lincoln, 2005). Its primary strength: the ability to construct meaning in a complex manner. The goal is not generalizability but a meaningful explanation of the human experience of a phenomenon. In this case, the experience of fathering through advanced cancer. These insights can be used to shape interventions, policies and future research.

Attending to the challenges of living with an advanced cancer diagnosis while parenting young children is an ongoing process about which little is known particularly when the parent with cancer is the father. The qualitative method is well suited to

examining less accessible phenomenon as it allows the researcher to become familiar with a participants' understanding of their lived experience (Patton, 2002). It is amenable to specifics as well as complexities and makes a place for contradiction to have meaning yielding a deeper investigation into the true essence of the experience of fathers facing cancer that are held by the research participants (Daly, 2007).

In their paper examining qualitative and quantitative methods with cancer survivors in the United Kingdom, McPherson & Leydon (2002) argue that the qualitative “epistemological standpoint is critically important when dealing with people who, when interviewed are at a particularly difficult and vulnerable stage in their life course” such as those living with cancer (p. 229). They assert that a quantitative approach would be too rigid and fail to “recognize the importance of individual patient voices.” (p. 229). Additionally, Moynihan (2002) posits qualitative methods are especially useful when investigating issues of gender and the cancer experience.

Qualitative research methods allow for greater flexibility to follow the data wherever it may lead which can result in greater depth of understanding (Daly, 2007). It is critical to gather data that will enable reflection on the lived experiences of fathers facing advanced cancer without defining predetermined categories into which the data will correspond. The flexibility inherent in the qualitative paradigm makes these methods particularly suited to investigations of sensitive issues such as living with advanced cancer as it allows the participants to form and articulate their own reality (Dickenson-Swift, 2008).

The cancer experience is a temporal process. For many families in which the father has cancer this experience can extend over several months and even several years past the point of diagnosis, through treatment and beyond. Inherent in this experience is constant change such as changes in roles, emotional states, and physical abilities. Grounded theory methods are based on theoretical ideas that emphasize process and the “changeable nature of human experience” and are particularly well suited to understanding the “highly changeable nature of family reality (Daly, 2007, p.102). Grounded theory methods provide the flexibility to follow themes in the data as it emerges and enabled me to “reshape” and “refine” my data collection process (Charmaz, 2006).

Grounded theory methods were originally developed by Glaser and Strauss as a method for generating theory that is based on “data systematically obtained from social research” (1967, p. 2). In other words, theory was ‘grounded’ in the data. A grounded theory method allows the discovery of new information with the explicit intention of developing a substantive theory. This theory is used to explicate findings and provide a framework for future exploration (Strauss & Corbin, 1990) as well as practice interventions (Daly, 2007, Gilgun, 1994).

Over the years grounded theory methods have evolved to include a more constructivist approach that places the role of the researcher in a more central position while adhering too much of the same methodological guidelines (Charmaz, 1990; Charmaz, 2006; Daly, 2007). Social constructivist grounded theory assumes that “neither data nor theories are discovered” and that the researcher’s experiences and perspectives

along with the participants views are both critical pieces in the constructions of reality (Charmaz, 2006, p. 10).

This epistemological positioning of grounded theory methodology fits with the purpose of this investigation which is to formulate a substantive theory that helps explain the psychosocial experiences of fathers facing cancer. In this case, I was guided by Corbin's and Strauss' (2008) definition of theory as "a set of well-developed categories that are systematically interrelated through statements of relationship to form a theoretical framework that explains some phenomenon" (p. 55). The creation of a substantive theoretical framework that explains how an advanced cancer diagnosis impacts a father's psychosocial well-being and ability to parent can offer important insights that can inform the development of targeted interventions and public policies that support these families.

Charmaz (1990, 2006) and Daly (2007) describe grounded theory as offering a set of strategies that are meant to be flexible in order to fully represent the participants' experiences. In order to be responsive to the participant fathers in this investigation I applied the aspects of grounded theory that best represented their interpretations of their experience with advanced cancer. These aspects are detailed below and include the use of purposive and theoretical sampling, sensitizing concepts, constant comparative analysis, memo-writing, and a mindful development of codes that accurately link the data and the emergent theory (Charmaz, 2006).

The emphasis of this investigation was to better understand the subjective experiences of fathers parenting through an advanced cancer diagnosis and the meanings

they attach in order to inform a theory ‘grounded’ in their perspectives. I used in-depth one-to-one interviews to construct my grounded theory. There are two primary advantages to using intensive individual interviews. First this type of data collection fits with the process of building a grounded theory. Both the grounded theory process and this type of intensive interviewing are open-ended and emergent yet at the same time targeted and sculpted (Charmaz, 2006). Second, open-ended interviews are particularly effective at drawing out an individual’s subjective perspectives about their experience (Charmaz, 2006; Gilgun, 1994).

Design

Sampling. Given that the intent of this study was in-depth understanding of the parenting experiences of fathers with advanced cancer, a purposeful sampling design was employed. Purposeful sampling allowed the selection of participants whose experiences facilitated an understanding of the phenomena in question in this case, fathers parenting through advanced cancer (Patton, 2002). This is the strength of purposeful sampling and this technique was used to obtain 11 fathers.

Fathers eligible for inclusion in the study met the following criteria. First the participants were all currently living with a diagnosis with advanced cancer (stage III or IV) of various types. The inclusion of these specific disease characteristics were necessary to address the current gaps in the literature which over emphasizes those diagnosed with an early diagnosis. A range of cancer types was included based in part on my practice experience which indicated that the experience parenting was not as dependent on the type of cancer as on the severity of the diagnosis. In addition I wanted

to ensure a meaningful sample size. Second, the participants were to be at least three months out from the date of their diagnosis. This time frame was important as the initial weeks after receiving a cancer diagnosis are extremely challenging for patients and their families. These days are often consumed by multiple visits with members of the patient's care team as they determine and begin the course of treatment. Third, the participants were to be actively engaged in raising at least one child under the age of 18. *Actively engaged* was defined as being actively involved in the decision making and responsible for the child's well-being regardless if they were the primary caretaker or living in the same home. The maximum age of the child was determined as the legal responsibilities of the father change after their children reach adulthood.

In addition, I strived to include fathers who are traditionally underserved in our society. I attempted to seek out fathers from diverse racial and ethnic backgrounds, and lower socioeconomic status in order to add their voices to the literature.

Recruitment. Initially, participants were recruited from the two largest cancer clinics in the Twin Cities metro area: one public cancer center and one private cancer center. The two largest cancer clinics were chosen for inclusion in this investigation as these clinics provide cancer care services to a significant number of minority families (e.g. at least 15% of total patient population) and will offer a wider range of socioeconomic experiences.

The design of this study required collaboration with the staff at the two designated cancer clinics. Due to the federal patient privacy regulations delineated in the Health Insurance Portability and Accountability Act (HIPAA), the clinic staff was responsible

for carrying out the identification of the father participants. In order to further comply with HIPAA, the clinic staff identified eligible fathers and gave them prepared letters of invitation/consent (Appendix A). The letter of invitation described in plain language pertinent information about the study including a brief description of the study purpose, procedure, risks, benefits and method of contacting the principal investigator with questions or intent to participate. Unfortunately, this method resulted in only one father contacting me to participate over the course of six months.

I then worked with the University of Minnesota Institutional Review Board to expand recruitment to include local community organizations serving people living with cancer. Flyers were prepared and posted in common areas in two community organization that serve a wide range of people living with cancer (Appendix E). In addition, I specifically sought guidance for how to recruit participants from my own organization in a way that was ethical and delineated my roles clearly. Staff at the organization where I am employed mailed and emailed letters of invitation to men they identified as fitting the criteria for inclusion. These expanded efforts resulted in 11 fathers expressing interested in being part of the study. Participants contacted me by email and phone at which time I confirmed their eligibility. Only one father didn't meet inclusion criteria as his cancer diagnosis was not advanced.

Interview location. Interview dates, times and places were mutually agreed upon. Interviews took place at a variety of locations and included, at one father's business office, at the homes of four fathers, three fathers elected to be interviewed at my office,

one father in a conference room at the cancer center where he received treatment and two fathers selected to meet in coffee shops near their homes.

Protection of human participants. This study conformed to the guidelines of the Institutional Review Board as well as the Cancer Protocol Review Committee of the University of Minnesota. Each father was informed that his participation was voluntary and that they could withdraw at any time without consequence.

At the start of the interview participants receive a \$25.00 gift card, a brief explanation of the study was given verbally and fathers were given the opportunity to ask any questions. Participants were informed that all audio tapes would be kept in a secure location and that the contents of the interview would be kept confidential. A written consent form (Appendix A) was provided that included consent to audio tape the interviews. Consent forms were then completed. Each participant received a copy of this form to keep.

At times during the interviews, participants experienced emotional discomfort while sharing their stories. When a father became emotional, I would wait to resume until they indicated they were ready to proceed either verbally or by decreased emotionality. I made information available to the participants about supportive resources available to them in their area.

Sample Description

Participant	Diagnosis	Time since diagnosis	Number of Children	Employment status at time of interview	Treatment Status at Time of Interview
Charlie ³	Glioblastoma, Stage 4	6 months	3	Long-term leave	In treatment
Chris	Glioblastoma Stage 4	3 years, 6 months	1	Long-term leave	Watchful Waiting
Mike	non-Hodgkin Lymphoma Stage 3	1 year, 10 months	2	Long-term leave	Watchful Waiting Treating GVH
Scott	Colon Stage 3	1 year, 8 months	6	Unemployed	Watchful Waiting Treating organ complications
Tim	Colon Stage 3	2 years, 8 months	3	Unemployed	Watchful Waiting
Gordon	Pancreatic Stage 4	3 years, 2 month	1	Long-term leave	In treatment
Eric	Multiple Myeloma Stage 3	1 year, 10 months	2	Employed Fulltime	Watchful Waiting
Bob	Pancreatic Stage 4	6 months	2	unemployed	In treatment
Mark	Soft tissue sarcoma Stage 4	6 years	3	Employed Fulltime	Watchful Waiting
Gene	Multiple Myeloma Stage 3	1 year, 10 months	3	Unemployed	Watchful Waiting
John	non-Hodgkin Lymphoma Stage 3	6 months	2	Full-time student	In treatment

Demographic variables. Research participants consisted of fathers who were responsible for raising children under the age of 18 years old at the time of their diagnosis. The number of children living in the household ranged from one to six. The

³ All names are pseudonyms

children's ages ranged from 18 months old to 28 years old. All of the participants were married. The participants were predominantly Caucasian (n=8), Latino (n=1), African American (n=1), African (n=1). Prior to diagnosis, 10 of these fathers worked outside the home in a variety of occupations, including construction, finance, health care, custodial, sales, clergy, and military. At the time of the interviews nine of the fathers were not working and eight of those participants reported that Social Security Disability (SSD) was the sole source of income in the household. Of the three fathers not receiving SSD, their household incomes placed them in middle to upper socioeconomic status. The level of education included, high school diploma, trade school, college, and graduate school.

Disease characteristics. Research participants consisted of 11 fathers living with a diagnosis of either stage 3 or stage 4 cancers. Their diagnoses included the following types of cancer: glioblastoma/brain tumor (n=2), non-Hodgkin lymphoma (n=2), colon cancer (n=2), pancreatic cancer (n=2), multiple myeloma (n=2), and malignant fibrous histiocytoma (MFH), a soft tissue sarcoma (n=1). The time since diagnosis ranged from six months to six years.

The following summary uses the classification system as outlined by Rolland's Family Systems Illness Model (1994) to further describe the characteristics of the participants' diseases and includes a description of onset, course, outcome, incapacitation, and level of uncertainty. This schema serves to link the "biologic and psychosocial worlds" in order to better "clarify the relation between chronic illness and the family" (Rolland, 2005, p. 2585). These categories provide a context to the disease which enables a more meaningful understanding that goes beyond a simple diagnosis.

Onset. Each of these participants described the onset of their disease as gradual beginning with early symptoms that seemed innocuous such as: headaches, forgetting things that should be easily recalled, blood in the stool, abdominal pain, back pain, a fussy digestive system (cramping, diarrhea, constipation), extreme fatigue, weight loss, difficulty breathing, coughing, restlessness, difficulty sleeping, bone fractures, sore muscles. The majority of these symptoms would come and go and initially were easily explained away by the participants and or their physicians as due to: dehydration, hemorrhoids, working too much, traveler's diarrhea, hunger, poor eating habits, a "flu" or "bug", a pulled muscle, too much exercise, not enough exercise, aging, etc. But persistent symptoms eventually led the participants to continue seeking various treatment and tests until the typical, less life-threatening causes had been ruled out over time. For some men this process took a few months for others it took several years (up to four) eventually leading to a diagnosis of cancer.

Course. The majority (n=7) of these participants' disease courses could be described as progressive. Rolland defines a progressive disease course as a gradual deterioration in health with few "periods of relief from the demands" of the disease (2005, p.2586). The other four participants could be described as having a disease course that would be considered more relapsing or episodic in nature. These participants will have longer periods with stable health with intermittent episodes of an outbreak or recurrence.

Outcome. In the FSI model the outcome is described as the degree to which the disease will impact a person's life span. The participants shared their understanding of

their prognosis at the time of diagnosis as ranging from six weeks to several years. All but two participants had been told their cancers were not curable and that the goal of their treatment was to either contain the cancer for as long as possible or to place the cancer into a type of “remission” for as long as possible. The other two participants described their cancer as curable thus that was the goal of their treatment.

Incapacitation. Each of the participants reported extreme levels of incapacitation at various times during their cancer experience thus far. These impairments included both physical and cognitive incapacitation.

Level of uncertainty. The participants in this study described a pervasive uncertainty regarding what the future might hold for them both in terms of the disease (e.g. trajectory of the disease, the impact of the treatments and the outcome) and ability to fulfill their father roles (e.g. their ability to provide for their family). For each of the participants the degree of uncertainty about the progression of the disease was high. At the time of the interviews this uncertainty about how their disease would respond to treatment was experienced nearly daily (n=9). Two participants had reached a point of stability where the uncertainty, while still present, was significantly diminished until the time for their scheduled check-ups arose.

Data Collection Procedure

The cornerstone of a solid grounded theory is “rich” data (Charmaz, 2006; Patton, 2002). As Daly (2007) notes, you can have rich data and still turn out a bad study but you cannot have a good study without it. Many authors describe rich data as a detailed and holistic description that enables the reader to draw their own ideas about implication

and importance (Charmaz, 2006; Corbin and Strauss; Patton, 2002). This data collection plan was designed to gather data that meets these principles using the intensive interviewing process as described by Charmaz (2006).

Interview plan. Intensive interviews have great potential to yield rich data (Daly, 2007). In person interviews are particularly effective when researching sensitive topics with vulnerable populations such as those living with chronic illness (Charmaz, 1990; Dickson-Swift, 2008; Mcpherson & Leydon, 2002). The consideration of an interview plan for gathering data on a sensitive topic such as a cancer experience requires attention to a number of issues. The ethical considerations related to this potential distress are discussed below. Dickson-Swift and colleagues (2008) describe the main concern as the potential stressfulness for both the researcher and the participant. There is some disagreement about whether it is preferable to structure the research to include one interview or use a more longitudinal approach (Dickson-Swift, 2008).

For this study I intentionally decided on a single, in-depth interview per participant. Dickson-Swift, James & Liamputtong (2008) offer an insightful discussion of the advantages and disadvantages of using a single or “one-off” interview versus having multiple contacts when conducting research with people in vulnerable situations. These authors note a chief advantage to having multiple contacts with a participant is the ability to establish rapport while a participant in a one-off interview may be more likely to reveal sensitive information. Additionally a single interview can be less taxing for those living with an advanced cancer. I arrived at the decision to conduct one interview per participant after receiving constructive feedback from other oncology social work

researchers that expressed concern that the number of interviews may be problematic for two reasons: first, the respondent burden may be too heavy; and second, the respondents' state of health or illness over the course of a longitudinal interview schedule may impact my ability to complete all of the intended interviews. I too was concerned about respondent burden primarily and decided a single interview would alleviate this burden considerably without impacting the value of the study.

The length of the interviews was influenced by the capacity of the participants and ranged 60-120 minutes in length. Each interview was semi-structured and included a few preset, open-ended questions and ready prompts (Appendix D). The questions explored the participant's view of fathering through cancer and comprise the following broad themes: (1) a description of their family; (2) a description of their diagnosis; (3) their understanding of how this diagnosis has impacted them as individuals and their family; (4) their perspective on what it means to be a father with cancer; (5) support received and the perceived need of additional support. Each of these general areas of initial exploration evolved from the sensitizing concepts described above which included a combination of my practice experience, personal experience, extant research, theory, and suggestions from my panel of community advisors (described in detail below).

Following the principles of grounded theory, the interview questions served as guides and not a rigid template to which I adhered. The initial interview guide provided some structure at the start of each interview. Charmaz (2006) suggests guidelines for ending interviews with the chronically ill that take into account the likely intensity of the conversation and recommends that the concluding questions leave the participant

“feeling positive about themselves” (p. 1167). Specifically questions that elicit their perspectives about personal or familial growth during their cancer experience. This suggestion fit with my clinical experience of working with parents facing terminal cancer diagnoses and thus each interview adhered to these ending guidelines.

Initial sampling moved to theoretical sampling in an attempt to reach theoretical saturation of the core research categories through constant comparison (Charmaz, 2006; Glazer & Strauss, 1967). Theoretical sampling differs from initial sampling in that it is concerned with obtaining data that explains categories that progress to theoretical development not simply the representation of a particular population (Charmaz, 2006). Daly (2007) likens this process to that used by photographers when they continually narrow and refine their focus until the picture makes sense. I began the processes of theoretical sampling after I identified my initial categories (Charmaz, 2006). I continually returned to my data to address new questions or concepts until I reached a point of theoretical saturation. Theoretical saturation occurs when new or relevant data no longer seem to be emerging from the particular category or theme, when the core theoretical categories have been well developed, and when the association between categories or themes has been visibly demonstrated (Charmaz, 2006).

Field notes and memos. Immediately upon completion of each interview I recorded detailed observations about the process including a description of the interview location, expressions and body language of the participant, and my own reactions to the interview. Beyond these primarily observational field notes, I maintained a memo-writing routine putting to paper my thoughts and insights garnered as a result of each interview.

Memos are used in qualitative research as a written record of our analysis process (Corbin and Strauss, 2008). The memos allowed me a place to formulate ideas and questions that served to advance this investigation. These records bridged the data collection and analysis process as I continued to connect and sharpen my codes and themes (Charmaz, 2006). The memos also served as an opportunity for me to engage in dialogue with myself in such a way that facilitated the separation of the “researcher from the researched” (Charmaz, 2006, p. 1169). This was an invaluable tool for me given my closeness to the topic.

Data management. Each interview was audiotaped so that I could attend to the responses of the participants without being overly concerned that I would miss a critical piece of their description. I personally transcribed each interview into a Microsoft Word document. The audio voice files were stored in a locked file cabinet in my home. All Word files were password protected.

Data analysis and interpretations. Qualitative analysis is based on data “reduction” and “interpretation” aimed at identifying categories and themes. In this study grounded theory methods were used to move these categories and themes into a substantive theory (Charmaz, 2006). Data analysis followed Charmaz’s (2006) guidelines for qualitative research using grounded theory methods and began after the first interview and continued throughout the data collection process. The data produced in this study included interview transcripts, fieldnotes, and memos. Consistent with grounded theory traditions the data collection and analysis proceeded simultaneously using the constant comparison method (Glazer & Strauss, 1967; Charmaz, 2006).

Coding. Constant comparative method is an analytic process in which collected data is continuously compared with new data and existing interpretations (Daly, 2007; Glazer & Strauss, 1967). This process forms the core of grounded theory generation as it compares and contrasts the data across categories and themes seeking patterns that yield theoretical explanation (Daly, 2007). One key way in which data can be continuously compared is by means of coding. Coding is the process of developing concepts from the data (Corbin & Strauss, 2008) eventually leading to the emergence of a theory that explains the phenomenon (Charmaz, 2006).

The data was downloaded into the qualitative data management computer program NVivo10. I used NVivo10 to store, code, and organize the data during the analysis stage. Charmaz (2006) describes grounded theory coding as including two main phases: initial and focused. To generate a theoretical explanation of fathering through cancer, the initial phase of data analysis began with a line-by-line examination of the data. This text was then openly coded over multiple reads in order to breakdown the data into coherent and meaningful categories a process known as open coding (Daly, 2006; Glazer & Strauss, 1967). This process generated a list of codes that were descriptive (e.g. definition of hope) as well as in vivo codes that directly used the fathers' own words to label and categorize sections of text (e.g. use of "provider" to label their construction of one of their father roles).

I then moved into the more focused phase of coding, axial and selective coding. Axial coding relates categories to subcategories formed during initial coding and puts the data back together again in fresh ways that interconnect the categories (Glazer & Strauss,

1967; Charmaz, 2006). As coding is not a linear process, I found it effective to intermix open coding with the axial coding. Selective coding is when the “theoretical story line” is created (Daly, 2006) through the process of integrating the categories that emerged through open and axial coding.

Adhering to the principles set forth in the constant comparison method, throughout this process I continued to check my interpretations against various sources including first and foremost the data. This process of constant comparison allowed me to substantiate my conceptual structure as it emerged enabling me to check the data for evidence that was either corroborative or disconfirming as I elevated my codes to categories. The next step was to move beyond merely descriptive categories toward a more conceptual description that still included the initial set of codes leading to the larger conceptual domain of resilience and a grounded theory describing the resilience process of fathering through advanced cancer. In addition to examining the data throughout the analysis I also considered my sensitizing concepts as well as consulted with members of my committee, other oncology social workers and one member of the community advisory panel of fathers.

Community Advisory Panel

A volunteer advisory panel of fathers from the cancer community was assembled prior to data collection with the goal of helping me shape my initial questions and then serve as guides over the course of the study. Originally, this panel consisted of four men parenting children under the age of 18. At the time two of these men were living with advanced cancer, one had completed treatment and showed no evidence of disease, and

one was a caregiver to a spouse diagnosed with advanced cancer. The inclusion of a caregiver was intentional as he offered a differing perspective than the fathers with cancer that helped to both broaden and deepen the direction of the initial research questions. The four men came from differing professional backgrounds and differing economic positions. They agreed to advise my research process from data collection through data analysis and dissemination as they were able to do so. Unfortunately, the two fathers who at the time were currently living with advanced cancer passed away prior to the start of data collection. The wife of another father entered hospice and passed away during the initial stages of data collection. As a result, one father remained as a much valued advisor.

Verification of Interpretation/Credibility

The value of qualitative research turns on the researcher's ability to keep the data, the interpretations, the reductions, and the resulting conclusions closely linked to the data from which they emerged. Toward that end, I worked to scrutinize my efforts to ensure that my interpretations were relevant, fit the data and could be considered credible (Charmaz, 2006; Daly, 2007). Daly (2007) describes sound qualitative research as demonstrating credibility in both the procedures and the outcome. In order to demonstrate credibility in my procedures I made certain that my process decisions were transparent and well documented through the use of detailed memos leaving what Lincoln and Guba (1985) refer to as an audit trail. These memos also included a reflexive description of how my role as the researcher informed and shaped the research procedures to the best of my ability.

Credibility of outcome was sought by triangulating my data through the use of the father on my advisory panel as well as checking my interpretations with the research participants as they were able for verification to ensure my findings made sense to them (Charmaz, 2006).

For qualitative research outcomes to be considered credible they must demonstrate that these findings fit the data (Daly, 2007; Gilgun, 2005). One way to demonstrate fit is through the use of rich description that enables the reader to feel they have been “vicariously” immersed in the experience (Glazer and Strauss, 1967). This can be accomplished by the appropriate use of participant quotes (Gilgun, 2005). Providing detailed quotes from the participant allows the reader to determine if I have accurately interpreted the participant’s view (Charmaz, 2006). I strived to align my interpretations with quotes from the fathers in this study throughout the analysis process.

Ethical Considerations

Undertaking research into the experience of living with a life-threatening disease such as cancer requires an acute awareness of ethical considerations. The four basic ethical principles of respect for autonomy, non-maleficence (do no harm), beneficence, and justice were carefully attended to in this study (Beauchamp & Childress, 2001).

Respect for autonomy was addressed in the informed consent process (Appendix A) and by allowing the participant to designate the location for the interviews. As a social worker I am guided by the core values of the profession to **do no harm** and strived to ensure that the **benefits outweighed the potential risks** to the fathers participating in this research project. I was keenly aware of how vulnerable these participants were both in

terms of their physical ability and their emotional state. For several of the men, the interviews elicited emotional responses that were painful. Yet, each of the fathers described the opportunity to share these strong emotions in the telling of their stories as having a cathartic effect (Daly, 2007; Morse, 2000; Rosenblatt, 1995) and several stated they were pleasantly surprised by this outcome. One father in particular described the experience as empowering as it was the first time someone listened to the whole story in a way that enhanced understanding and normalized his experience. This phenomenon has been noted in the literature (Dickson-Swift, 2008). Daly (2007) suggests having a ready source of resources should the participant inquire. Two fathers requested information about organizations that could address their legal and or financial concerns. I had a list of resources available and provided suggested contacts (Appendix D).

The fourth ethical principle is **justice** meaning that the research should be fair and just (Beauchamp and Childress, 2001). Some debate exists around whether it is just to conduct in-person interviews with people living with a terminal illness (Dickson-Swift). Morse (2000) responds to that debate saying,

It is immoral not to conduct research with the critically ill or dying; they are the most disenfranchised members of our society and most in need of understanding. Qualitative research can provide insights into their experiences, their discomforts, and their needs and show how care can be improved and their needs met. (p. 545).

I concur and believe the knowledge gained from these interviews has the potential to benefit the individual participants as well as others who are impacted by a similar experience if the knowledge gained is used to inform services and policies that meet their specific needs (Dickson-Swift, 2008). Fortunately, given my position as a director of

programs serving families raising young children while facing a parental cancer diagnosis, I am uniquely situated to immediately use this knowledge to shape our programs.

Finally, I was very intentional in the language I used throughout this project both in written as well as spoken form. I worked to always use person-first language for example, referring to participants as fathers living with cancer rather than cancer patients. In addition, I used language that was strengths-based. For example, over my years of practice I have heard numerous individuals striving to live well in the midst of this life-threatening disease take issue with the term, *cope*. For many, this word has taken on a meaning that seems to imply a state of barely getting by more closely akin to treading water than to swimming. Out of respect for that perspective, in my practice work I have shifted from using the terms *cope* or *coping* to the preferred terms *face* or *facing* as well as the phrase *meet* and *manage*. Thus these are the terms I use in this paper.

CHAPTER FIVE

Findings

The findings presented in this paper focus on the experience of 11 men living with a diagnosis of advanced cancer while parenting young children and center on the conceptual process derived from the interviews that was eventually described as *fathering with resilience*.

In this chapter, I present these findings. I begin with a definition of resilience followed by an introduction of the grounded theory I constructed that arose from this analysis, the Resilience Process of Fathers Living and Parenting with Advanced Cancer. I then provide support for this theory by way of the description and analysis of the participants' experiences.

From the moment of diagnosis their role as a father shaped the cancer experiences of these participants as much as the demands of the cancer shaped their experiences as fathers. The participants' experiences were rich and complex and laden with uncertainty and loss. However, this analysis ultimately revealed that these experiences were permeated with resilience in the face of the extraordinary life challenge of fathering through advanced cancer. Consequently, *fathering with resilience* became the conceptual umbrella that contained their experiences.

As discussed earlier, the definition of resilience has evolved over the last several decades from primarily an individual personality trait to a more nuanced definition that

describes resilience as a process that includes a relational component (Wright, Masten & Narayan, 2013). The experiences of the fathers in the present study support this more nuanced definition of resilience that aligns somewhat with Boss's (2013) description of resilience in the face of ambiguous loss as the "tolerance for long periods of ambiguity, and the ability to thrive and even grow stronger despite the lack of clarity about a loved one's absence or presence. It means managing the anxiety that comes with not knowing" (p. 285).

While ambiguous loss more accurately describes the experience of the family members of these participants, ambiguity and loss were certainly part of the fathers' stories. Walsh's (2006, p.4) definition of resilience as a continual act of "endurance, self-righting, and growth" precisely captures the participants' experience facing cancer day-in and day-out while parenting young children. Their active *desire* to live well leading often to the *ability* to live well while balancing between hope and despair in the midst of uncertainty or what one father labeled "the mystery" demonstrated resilience. Thus, resilience, in the context of fathers living and parenting with advanced cancer is defined as the ability to live and parent from a place of hope in the midst of uncertainty.

Grounded Theory of the Resilience Process

These findings demonstrate that fathering with advanced cancer can be a grueling experience filled with change, uncertainty and loss. Throughout the interviews fathers described the challenge of having to balance between hope and despair. One father specifically used the phrase "teeter-tottering between hope and despair." The decision to use a teeter-totter layout to depict the resilience process arose out of this language. This

balancing act was described by the fathers as an ongoing, daily and at times a moment by moment endeavor that crossed various domains of their life. Resilience was exemplified in their active *desire* and eventual *ability* to live in and parent from a place of hope – hope for the treatments to be effective; hope for the cancer to be contained; hope to live as long as possible to be there for their children. The question then becomes what tips the balance in favor of hope? This model, grounded in the findings of the present study, offers some suggestions (Figure 1).

Though conceived independently, the model presented below is similar to the Family Adaptation and Adjustment Response Model (FAAR). The FAAR model conceives the process of resilience as balancing the demands of a crisis with a family's capabilities, along a continuum of maladjustment and bonadjustment (McCubbin & Patterson, 1983; Patterson, 2002). This model of family resilience illustrating a family's balancing act closely parallels the resilience process of fathers living and parenting in the face of the specific threat of a father's advanced cancer along a continuum of hope and despair (Figure 1).

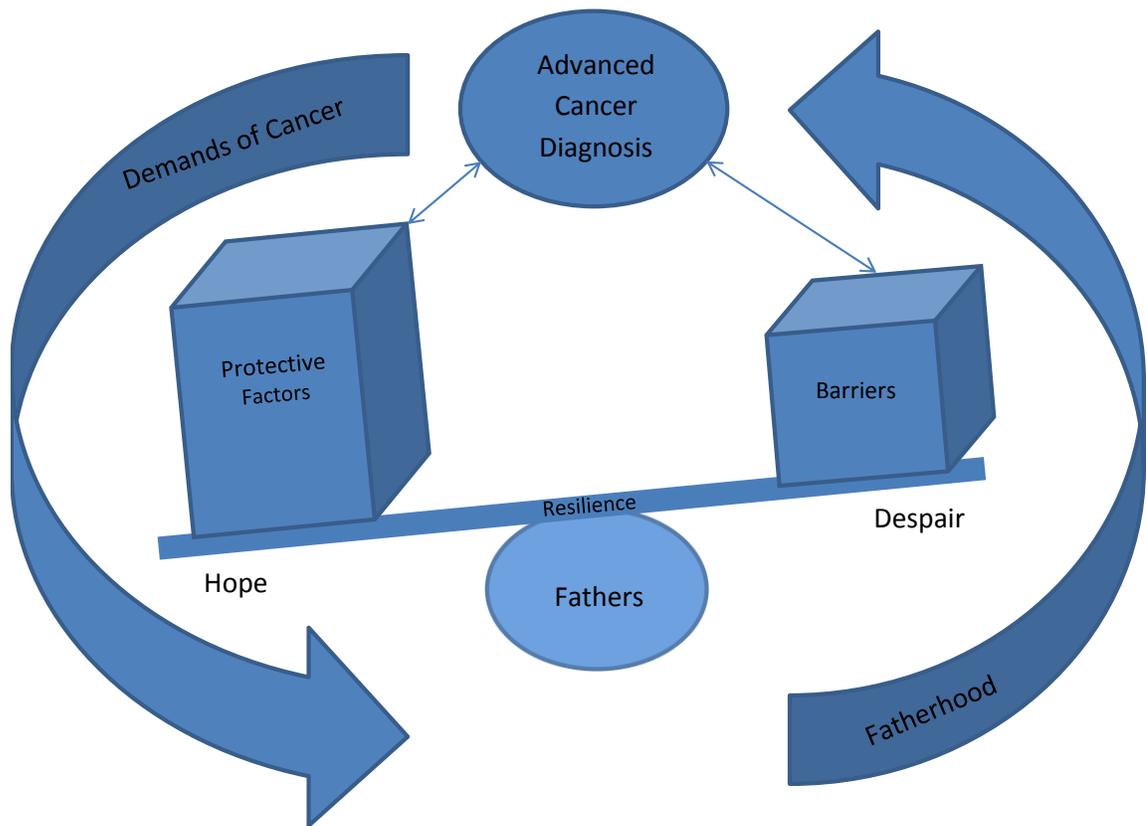


Figure 1. Resilience Process of Fathers Living and Parenting With Advanced

As my model of these fathers' resilience evolved over the course of data collection and analysis, I had been uncertain about where to place the cancer diagnosis in my model. The FAAR model shaped my decision to place the cancer at the top. While family resilience theory does not necessitate the presence of a significant risk exposure (Patterson, 2002; Walsh, 2006), a diagnosis of advanced cancer qualifies as such. Thus the diagnosis of advanced cancer is represented in the oval at the top of the model. The fathers are placed at the fulcrum to denote their central position in the resilience process and their ability to counterbalance the weight of the barriers with a greater quantity of protective strategies. A reciprocal, mutually influencing relationship was found between the privileges and responsibilities of fatherhood and the demands of the disease. The

arrows that surround the model suggest this dynamic process by identifying the two ongoing feedback loops.

Embedded in the resilience process of these participants were pathways that served to alter the effects of this disease in their lives. In the literature these pathways have generally fallen into two categories described as risk factors and protective factors (Masten, Best, & Garmezy, 1990). The risk factors act as potential barriers in the resilience processes while the protective factors support the process of resilience (Masten, Best, & Garmezy, 1990). The fathers used terms such as “hurdle” to describe the risk factors. As a result, in the model I have decided to use the term *barriers* to represent those risk factors as it more closely corresponds with the participants’ own language. The description of the barriers and protective factors that shaped the resilience process of these fathers is presented using the lens of family resilience theory as described by Walsh (2006) and Joan Patterson (2002), to investigate this process as it developed across their cancer experience.

The fathers described several barriers challenging their resilience. The analysis suggested three barriers experienced by these fathers were particularly salient to the resilience process: level of impairment, level of uncertainty, and degree of financial burden. The following protective strategies were used by the fathers to navigate these roadblocks enabling them to tip the balance in favor of more time living and parenting from a place of hope: role flexibility, open communication patterns, appraisal-focused skills, utilization of supportive resources, and finding meaning.

Reciprocal relationships were also found between the demands of the disease and the barriers experienced by the fathers as well as the protective strategies they utilized. The smaller two-directional arrows represent these interdependent processes. For example, the various treatments and procedures the participants underwent often resulted in diminished level of functioning and, in turn, a diminished level of functioning could reduce their ability to receive further treatment. Several fathers described experiencing compromised immune functioning due to a reduction of their white blood cells, a condition called neutropenia, which led to various infections that, in turn, disrupted further chemotherapy treatments until the infection was controlled. Similarly, the effective use of protective strategies in response to the disease-related demands could lessen those demands, and in turn, lessen the need for those protective strategies. For example, worries about future tests and procedures can act as impediments to keeping those appointments. Many of the fathers were able to compartmentalize their worries in a manner that enabled them to adhere to their treatment plan.

Finally, hope and despair are placed at either end of the lever of resilience. The dialectic between hope and despair was found to be an ongoing rather than a linear process, linked to the balance the fathers were able to achieve between their protective strategies on the one hand, and the barriers on the other hand. The findings suggest these fathers conceived of despair as the absence of hope. Hope was found to be a critical landing point in the resilience process of these fathers. Each of the fathers had a clear grasp of their dire predicament. Theirs was not a false hope but one grounded in a clear understanding of the potential threat. This type of hope has been described as crucial to

resilience (Boss, 2013; Walsh, 2006). This model, grounded in the experience of fathers living with advanced cancer, supports this assumption.

I decided to present these findings in a temporal order as that most closely aligns with the experience of the participants. The findings begin with a summary description of the early symptoms these fathers reported then move to the experience of finding out the specific diagnosis and prognosis leading into their experience fathering through cancer examining how they made treatment decisions, how they explained their disease and prognosis to their children, how living with cancer impacted their ability to fulfill their perceived father roles, their experience with support and conclude with their attempts to find meaning. At each point along the continuum of the cancer experience I will explicate the barriers and protective factors that shape the process of resilience.

Throughout the collection and analysis of the data I expected to find differences in the fathers' experiences that were shaped by their various demographic characteristics. As mentioned above, the participants varied in their socioeconomic status, race and ethnicity. However, in this cohort of 11 fathers, these variables didn't appear to impact their experiences parenting with advanced cancer. As the findings below suggest, the most salient characteristic influencing their parenting experiences was a disease-related characteristic – impairment. The level of impairment experienced by the fathers as a result of the presence of the cancer in their body as well as the impact of the necessary treatments, shaped their ability to parent and thus sharply influenced their process of resilience.

Finding Out

“You have cancer.”

Charlie: We had to do studies to determine how the masses got there so if they're from the brain then we do surgery and if they are from another cancer somewhere else in the body and they metastasized ... either way they did tests on my kidneys and my lungs and any mark on my body for melanoma all that stuff and finally determined that it was most likely cancer of the brain.

The findings of the present study reveal various barriers to resilience in the face of disease and arise even prior to the actual diagnosis. A pervasive sense of uncertainty permeates the process of finding out whether or not they have cancer and the specific type of cancer diagnosed. Due to their early experiences with various symptoms the process of discovering their specific diagnosis took place over time and often meant several days of multiple tests, scans, and invasive procedures to conclusively diagnose their cancer type and stage. The above quote from Charlie is illustrative of what this entailed and the uncertainty inherent in the process of discovery an experience shared by each of the fathers in the study.

In response to finding out the specific diagnosis and the potential gravity of the outcome the fathers reported a range of emotional reactions including shock, fear, confusion, and resolve.

Charlie: They pulled everybody into one spot, me and my wife and maybe eight other people that cared and told me what it was and it was bad. And everybody started crying and I was looking around and I didn't know what to do and everybody was crying. Um my brain was a little off but I know what they said, Glioblastoma stage four. But I'd never heard of it before and when everybody was I crying. I was like this is bad. ...the surgeon who was telling us it was stage four. It was a pretty negative conversation, she [his wife] said, “can't you be hopeful or can't you be positive?” He [the surgeon] said, “I can't be positive, I can't be negative, I gotta be realistic. You guys are up for a big battle” and so she said, “is there anything we can do?” and he said, “pray and get something to grab onto.”

Chris: I remember going into one of those machines and they said, I don't really remember but they said I had cancer and they didn't know what kind and then... One thing I do remember is my sister ...she asked the doctor, "is he going to make it until his kid graduates" and he said, "I'm not going to say. I'm not going to put that number out there." And then I really realized it was bad. ...the doctor who did the surgery said I would make it 6-12 months. That's all he would give me. And I just thought he's wrong. He's wrong; I'm not going down for this.

Scott... I'm in the room laying down there and the nurse is there talking to me and she's just chatting me up left and right and so is the doctor and all of the sudden them two start whispering. And I'm going what the heck and he starts telling me, "I'll be right back." So he runs and gets Dr. Smith, who ends up being my surgeon, and they're standing there like two... just whispering back and forth. And all of the sudden the nurse who had previously been behind me and I could see this monitor and now she is blocking the monitor. So I, there was a mass probably, oh about the size of this thing right here [about a golf ball] and I'm staring at it, I'm looking at it, cause it looked like a big eye staring back at me cause she finally moved and I go, "what's that?" And the nurse looks at me and says, the doctor will be right in and you need to get dressed and the doctor will be in in a couple of minutes to talk to you. That dude, he just came and blurted it out... and said, yep you've got colon cancer. She [his wife] was looking at me and I was looking at her and I wasn't even in that room when he said that I was no longer in the room I was just sort of ... I could hear everything but it was like a million people were in the background and that all that I heard was all their voices and but she [his wife] wasn't saying anything. ...Oh my god they're going to tell me this cancer thing is stage 3b so I'm not even sure what stage 3b means.

Tim: the group I was with was kinda starting to insinuate maybe there might be a cancer issue here but they didn't really know... I went in for a colonoscopy. He was there for five minutes and said Tim you have cancer in your colon and so you need to have something done about this. I asked him one time I said, "Doc do you think you can cure me?" and he said, "Tim I have no confidence that I can cure you but I'm very confident that I can get you into remission." At that point I had lost about 25 lbs. and I knew that something was seriously wrong and actually at that point it was a great relief to be diagnosed and as kind of perverse as that sounds it was like it really felt like I could precede with a plan. I have a diagnosis. I have cancer. Now we know so we can go forward.

John: The day that I was called back to the hospital they told me man you have cancer. They said it once but a heard it more than once. It re-echoed again. "John you have cancer." the doctor said it once but I heard it echoing again out of fear. Because the name cancer is very close to death, very close to death. When you have cancer, when someone tells you are diagnosed with cancer problem

somehow your mind is thinking when are you going to die? Is it possible for me to survive this? Pains you are going to go through if you are to survive this. After the cure will the cancer come back again? What will be the outcome of this? And so many other questions. So the news came to me like a big shock. Cause I least expected that ... that cancer would hit me at this moment.

Eric: So she took the blood test and found out my hemoglobin was way down and took a look at the x-ray and said I'm not sure but I think what you have is multiple myeloma. I said, "What's that?" and she said, "It's a cancer." "A cancer of what?" and she said, "it is a cancer of the blood and in your bones." She explained it to me a little bit but you know when she said you may have cancer, I was like really, me? I've never been in the hospital since I was born. You know, I've been pretty active, quit smoking a long time ago, social drinker so I don't abuse my body. Me cancer? It doesn't make any sense. And you know, the biopsy three days later confirmed it and then I'm in the oncologist's office being told you know you have the most aggressive form of multiple myeloma.

Bob: I was kind of leery something was up because I could tell the technician was spending a bunch of time on some things and then that night we got a call from the PA that unfortunately they found cancer in my liver and that they need to run an MRI. Everyone was here and you know all I can remember is just being in shock and just hung up the phone and said, "I have really bad news I have cancer and they want me to be at the doctor tomorrow for more tests." And [wife]'s like what? And you know we were all kind a in that stage of like what? So it was a shock, a huge shock. And you know at that point you don't know what to do. You're probably not going to sleep and wonder about the next day and the tests and what is that going to determine and how bad is it and ...It was like, wow, what me? A dad, 47,48 years old, been eating organic food for the last 20 years, living a relatively clean life, not super healthy but probably healthier than 90% of the people in the country. So it didn't make any sense. It didn't add up. It was such a whirlwind of confusion. Like, wow how could I be having all this cancer in my body? The first doctor we met with...gave us a very grim picture of how the statistics and said, "If you do nothing you might make it to Christmas."

First Concern was Family

"My first worries were what about my family?"

After the initial shock of finding out/discovering their diagnosis and prognosis, 8 of the fathers reported how their first thoughts turned to their children, revealing a connectedness and commitment to their children. This is the point in each interview where the fathers expressed the strongest emotion. They were amazingly stoic and factual

in their accounts of finding out they had been diagnosed with this life-threatening disease and for most of the men a terminal disease until it came to speaking of concerns for their children. For these eight men, their voices were filled with emotion, the eyes welled and for many the tears flowed.

John: Yeah when I got the news you know I said my little children who I love so much would I leave them now? [He chokes up a bit] would I leave my wife? What would be the hope for these kids? Taking a look at the family where I come from I knew how I struggled and suffered to leave Africa to be here in order to make the future for my children to be brighter than mine. If I leave them through cancer through sickness what would be their future?

Bob: So you know my first worries were what about my family. What about my daughter really? ...So the biggest worry was well I'm gonna die soon, according to these doctors, what's gonna happen to my family? How's that going to impact them? Because I wasn't really worried about dying. I don't have worries about what happens in the afterlife for myself. I don't worry about that. That part I'm okay with. I don't want to die. I'm not in any hurry to go there but when that someday arrives I'm well prepared in my own faith I think. I can be okay with that for myself – but not for my family.

Eric: I think I shed tears once but it wasn't for me it was for my wife and my son, worrying about if the worst happens how are they going to navigate? So when I gathered my first, after I had cancer and I said jeez how is this going to affect my family? So whenever I've shed tears it hasn't been for me it's been for my wife or my kid or my mother.

Tim: I never feared for my wife cause she's strong. But the thought of walking out on my kids that was unbearable. ...So I never really feared for my life. I wasn't afraid to die and I'm not particularly brave. The thought of dying didn't bother me. ...Seeing my kids' life is precious. It still hurts. Um ...difficult to talk about obviously. It is the only thing that ever wrenches me up.

Gordon: So having an 8 mos. old son is hard you know my biggest fear is leaving him. Not that I don't feel bad about leaving her but she's an adult. She can rationalize it somewhat. Not that it won't be hard or sad but she can handle it. How does a toddler understand why dad's gone? Or why dad's not there anymore. Or is dad coming back? Okay, he's not coming back Does he love me?

These findings suggest that the uncertainty which permeates the initial days of a cancer diagnosis negatively influenced the participants' experience. Their fears for their own well-being combined with concerns for their family were elevated by this uncertainty challenging their process of resilience (Figure 2).

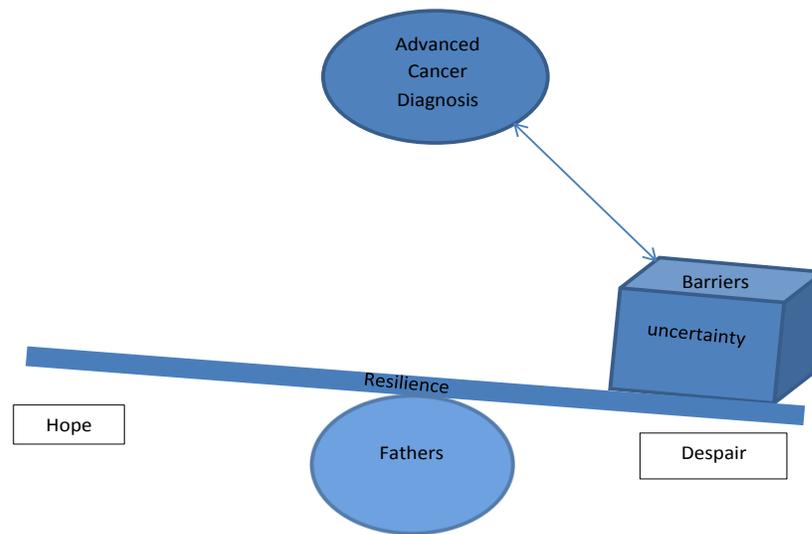


Figure 2. The weight of uncertainty in the resilience process

Communicating about Cancer with Their Children

“It’s tough to know. There aren’t any clear steps you take when you are parenting.”

A challenge faced by all the fathers immediately upon the discovery of their disease was finding a way to inform their children about their diagnosis. Uncertainty permeated their thoughts and decisions about how to approach the topic. These conversations often necessitated the fathers speaking about their prognosis and addressing their children’s fears that their father might die. The fathers struggled intensely with the challenge of having to balance the statistical realities of their chances

for survival with the genuine hope that they could “beat the odds” as they explained their cancer to their children. They also struggled with how to balance the needs of the child, their longing to protect their children and the desire to prepare the child for a potential future without a father.

Each of the father’s in this study made the decision to tell their children about the cancer diagnosis. Interestingly only one father expressed a serious desire to not tell his children. He was easily persuaded by his wife to change his mind:

Scott: And we had to wait for the operation and everything and I told her [wife] not to tell anybody just...

M: So you didn't want to tell your kids or grandkids?

Scott: No. Not at first no. Yeah but then you know she slowly talked me into telling everybody.

M: So how did that happen? How did she talk you into that?

Scott: Well you know she told me, she asked me if I was on the other end would I wanted be denied this information to maybe change... you know what I mean? And I thought and I said you know you are right, you're right.

The age of the children influenced how the fathers spoke to their children about the cancer. Three of the fathers had children that were younger than 3 years of age. These fathers reported finding it difficult to know what to say as their children were too young to fully understand. These fathers often used euphemisms to describe their circumstances. For example when asked how he explained this to his 3 year old son, Gordon described the conversation, “Daddy doesn't feel well. ...he's like, ‘You'll be okay daddy.’ He's sweet about it. I know he doesn't understand what's going on.” John shared a similar experience with his 2 ½-year-old daughter.

John: So like when I came back from the marking of my body for radiation when I removed my clothes my daughter said "daddy what is this?" I said, "The doctors had poked my body." So then she said, "oh sorry." The level at which they can know is so little.

Additionally, the uncertainty about what lay ahead compounded the fathers' difficulty finding the words to explain what was happening and what the future might hold.

Mark: my kids were young enough, you know 7, 5, and 2. I think my two boys were 5 and 2 really. I don't think we really even sat down with both of them cause to be honest at that time we really didn't know and they said ... my protocol was to go through chemo treatments first and then have surgery so obviously having never been through any of that I don't think I had an idea what we were in for and what was going to happen. So it was pretty difficult to have any sort of specific conversation with them. My 7 year old daughter asked me. I think we mentioned to her that I was sick and was going to have to go through treatment and we said it was cancer but again I don't think she got it at that time.

It became clear that talking to their children about the cancer was not a one-time conversation but a series of conversations over time. Regardless of age, the father's own uncertainty about what lay ahead made these conversations very challenging and a potential barrier to resilience. The fathers navigated that barrier with the decision to speak openly and honestly about the disease with their children. While the decision to tell their children was clear the fathers struggled with how to balance two seemingly dichotomous truths: the reality of the level of threat to their lives and the hope that they would survive. This uncertainty permeated their entire cancer experience as fathers including the process of explaining their disease to their children. They reported how they struggled to find a way to hold these two truths in these conversations.

Charlie: There is the block where you say you want to be honest but at the same time you want to have hope right? So I know it is possible to die and it could happen real quickly and part of me wants to prepare them for that. The other part of me is like, "no" because you gotta have hope. And the chances are slim that that [going quickly] is going to happen. So how much slim do you want to focus on? You know what I mean? ... But it is hard because how do you know? You want them to be prepared but at the same time you don't want them to be scared. That's the story and I still have issues with trying to make sure he gets that kind of teeter-tottering between hope and ... despair.

All of the fathers chose hope. One protective strategy they used to tip the balance toward hope has been described by Walsh (2006) as an "optimistic bias." This is captured in Mark's quote below:

Mark: yeah. I don't think we've ever had... we've had lots of conversations over the years with the kids not like sit down stuff but where they have questions... I don't think we've ever said daddy's better and have it go the other way where I've been re-diagnosed. I think we've always been pretty guarded... guarded optimism... with them about how things are going so um I don't think I've ever been terse or straight forward with them either and said, "hey this is not going away. I'm going to die from it." But um we've kind of said this is something we have to keep working on.

Inevitably the topic of death arose. With one exception each of the fathers reported having conversations about death with their children. The fathers reported these conversations were difficult especially given the challenge of communicating honestly about a topic that is charged with emotion and contains so many unknowns. It is impossible to be certain about the trajectory of their disease and the fathers had to find a way to make this clear while still being hopeful.

Eric: Cancer is ... I told him you know a lot of people have it. A lot of people die from it but a lot of people survive it. The kind I have you really don't survive cause there's no cure but there's treatment so it's not like I'm going, you know, fade away tomorrow but we're going to fight this, we're going to fight together

and I don't want you to worry too much. I'm giving him the real scoop but I'm not losing hope.

Only the father whose children are under 2 years of age has not spoken of death with his children as he feels they are too young to understand. One father with a 3-year-old has had general talks about death and has mentioned he may die but his child's understanding is limited by his developmental understanding of death. Additionally the father revealed these conversations are limited by his desire as well as his wife's hesitancy to discuss the topic. Despite the natural disinclination to talk about death he tries:

Gordon: We talked about death a little bit at one point but she didn't like me talking about it. I mean we can talk about it and he'll be like, "well I can get another daddy?" We generally talk about it like everything dies, animals die and eventually I'll die and then he'll joke about dying and you know but we have talked about death and how I'll probably die before you're older. We haven't figured out how. I mean we know there are some books but we just haven't gone there yet. Maybe part of us doesn't want to. Maybe we're afraid of scaring him. ...How does a toddler understand why dad's gone? Or why dad's not there anymore. Or is dad coming back? Okay, he's not coming back. Does he love me?

One father reported that his child, upon being told his father had cancer immediately expressed fears that his father might die.

Eric: He took it well. I mean he got emotional, you know, "Daddy when are you going to die? Are you going to die," he said. ...you know those first few weeks he was, "when are you going to die? I don't want you to die." And I said, "Well, not if I can help it but we all die," and you give him that we all die talk and then you know I said, "cancer," and I told him this repeatedly when he gets into these moods, "you know [son] there's a little baby being born right now that's not going to survive the hour. That little baby is not going to know what it's like to do the things I've done for 50 some odd years. So if I do die I die satisfied that I've lived a long time" and that tends to kind of calm him down.

In other families the fathers reported that the children's concerns about death were revealed over time. For example, one father shared how his 7-year-old son had experienced a very vivid dream about his father dying. This dream occurred the day before our interview. This father has been living with his cancer for more than 6 years and has had multiple recurrences.

Mark: My wife just called me, this was yesterday, and said that, I left for work at 6:45, she said he woke up at 7, maybe right after I left for work, just crying inconsolably and said that he had this real vivid dream that I died from cancer and was very, very upset and said he was very difficult to console probably because it was so vivid. When I got home from work yesterday he was, he gave me a big hug and sat on my lap and asking, "Are you okay?" I think he was trying to help himself to say that it was just a dream. He's fine. "You feeling okay dad?" I had talked to him a little bit about it and just asked him what his dream was but we didn't get too into details. I tried to reassure him that things were fine and that it was just a dream so but it was odd because he... this is not a common theme and this was the first time this had happened in 6 years where he or any of them have expressed that. We've had some emotional times before but nothing where they were inconsolable crying and wouldn't stop.

Another father shared how while he was in the hospital recovering from a major surgery he had called home to deliver some bad news to his wife about his need for additional treatment and his wife began crying. His 13-year-old son had overheard part of the phone conversation with his mother crying and feared the call meant his father had died.

Charlie: So she started to cry and then Anthony comes running downstairs, "did dad die, did dad die?" So you knew he was thinking it right? He never expressed it but he was thinking it. And that was probably the time that I realized it was weighing on his mind far more than I ever realized.

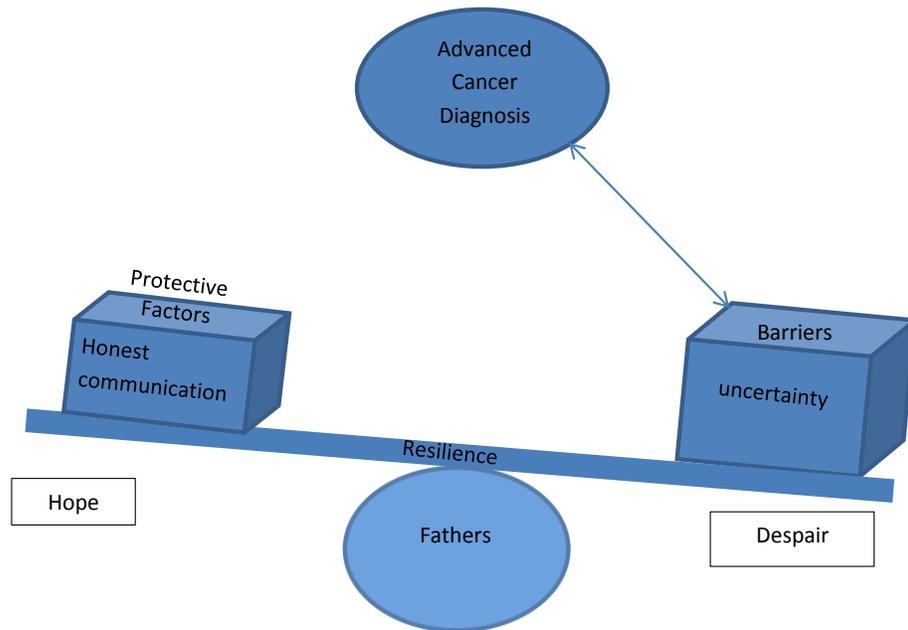


Figure 3. Honest communication as a counterbalance in the resilience process

As the findings indicate, in the face of uncertainty, over time each of the fathers choose to speak openly and honestly with their children about the cancer diagnosis by taking into account the age of their children as well as what they perceived their children needed to hear. This style of communication had a protective effect helping tip the balance of resilience toward hope (Figure 3).

Treatment Decisions

“And so then the journey began, where to go, who to see, what to do?”

The confusion and uncertainty continued as the fathers grappled with decisions about treatment. Where will they seek treatment? What type of treatment? This analysis suggests that fatherhood influenced these decisions in a variety of ways. For example, one father seriously contemplated going out of the state for treatment but his wife wanted

him nearby to be able to care for him and he realized that he just couldn't leave his daughter to do so.

Bob: Well at the time she is working full time and the kids are in school and she's like there is no way in the heck we are going to do that cause I'm not going to have you get treated and have to suffer through all this sitting in a hotel in Chicago by yourself or maybe a relative or two would come for a bit because we have relatives down there but... She's like, "no way I don't want that. Cause I want to be with you." ...I get to stay at home. I don't have to travel. Which is I think huge. You know being a dad, my daughter is going to wonder, where's dad? And my dad's in Chicago. You know it might have been nice to kind of hide it from her. You know hide the chemo and the effects but, I think it was better for our family to experience this to see what happens.

Another father chose to make a lengthy commute to a different city for treatment spending hours in the car each day. He and his wife could have stayed nearby the hospital and avoided the long often daily commute but chose not to so he could see his son each day.

Chris: Four hours - five hours of her day was driving me back and forth.... When people asked why I did it I said, "Well I don't know how much longer I'm going to have to see my kid. I don't want to leave him home."

The desire to live as long as possible for their children had an enormous impact on several of these father's treatment decisions during the course of their cancer experience. Many fathers expressed resolve to do whatever it takes to survive both out of concern for their children's well-being as well as out of the desire to be a part of their children's lives.

Bob: Well absolutely for me if it would have been left up to me only and I had no family and no reason other than to survive I probably would not have subjected myself to as much chemotherapy as I did. I really thought in my brain that I'm doing this for other people. Not for myself. I'm doing... for a while it was for me and then when it became really bad like you said I was feeling really horrible. At

that point, I just said I wasn't doing it for myself any longer. I was doing it... I switched. My mentality switched to doing it for my family and my wife and my kids and my desire and deep passion to continue to be here for them. I think out of that fear of what's going to happen to them if I'm gone and so there's almost that fear driven factor to take the chemo even though I didn't like it. You know it was harming me and it felt awful and I was in pain and misery.

Gordon: Why am I doing this? For him [his son]. If I didn't have him I don't know that I would. Not that I want to die but I guess I've come more to the acceptance level a few years ago that you know what happens if I don't make it to old age. I mean this is before I had anything that maybe I mean on a personal level I could accept it. I suppose. But when I had kids, I was like well now I have to be here you know.

John: Yeah, Yeah! Like leaving my very young woman, leaving my kids to die I say I had in mind that no matter what kind of medication the doctors will recommend to me no matter how bitter or how painful or how I feel when I am going through them. I must go through them so that I will be alive to take care of my family.

Beyond the motivation to live as long as possible for their children, some fathers expressed that it was important to them for their children to know they were doing everything they could to be with them. They wanted their children to understand that if they were to die, it wasn't because they chose to leave them but that it was the result of the disease.

Scott: you know I'm not a bad person and this is something that god ...not some punishment...you know that I'm just fine and hopefully you know that if the worst happens that my grandkids and kids would realize that I did my best and you know this is ...my time.

Charlie: I tell the doctors look, if something's going to keep me alive do it. ...I don't include the family on those decisions. I don't expect to tell them what I told them all along. That I'll do everything I can to stay alive so trust me on that. Whatever I do, no matter how painful it is. You know the dangers whatever, I'm going to do it if there is a hope that I can keep alive. ...I'm like after my kids saying that look, "I wanna be at your graduation. I wanna see you get married. I wanna touch a grandkid or two. So you know whatever it takes. I'll listen to the doctors and do whatever. Put it in me. Do what you need to do."

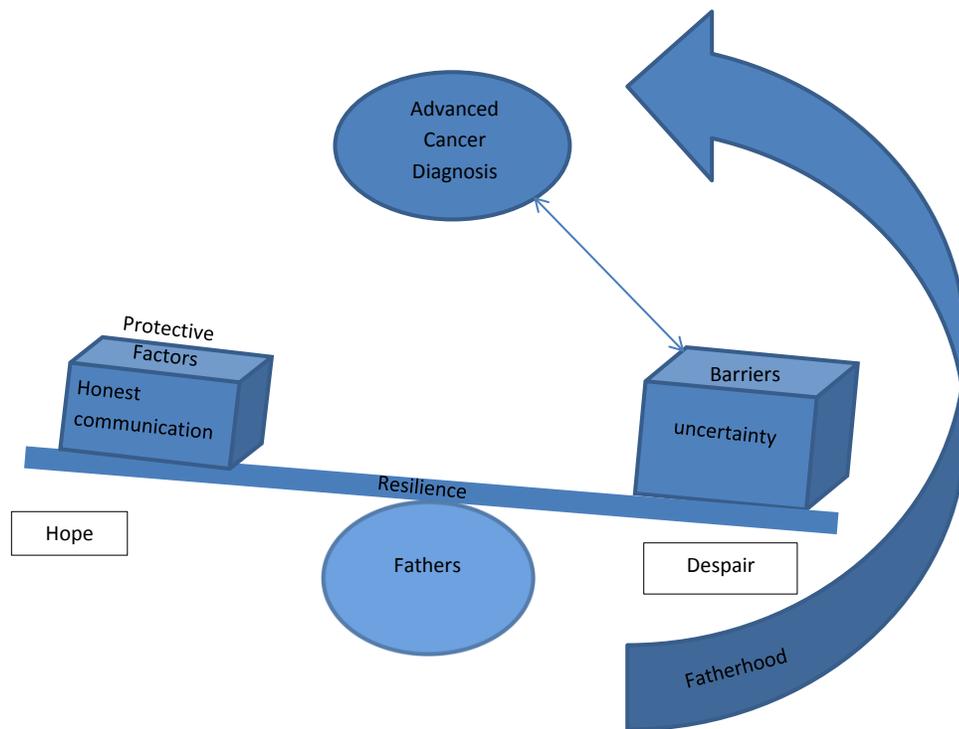


Figure 4. The influence of fatherhood on the disease experience

The findings suggest that by shaping their treatment decisions, the participants' status as a father potentially influenced their disease experience. This relationship between fatherhood and the disease experience appears to continue throughout the participants' cancer experience as they described at the time of the interviews. As the section below indicates, this relationship was reciprocal.

Cancer's Impact on Fathering

"You know in like four days your whole world changes."

As the above quote captures a cancer diagnosis brings change. For the fathers in this study this change was accompanied by uncertainty and loss especially once treatment

began. This section focuses on the fathers experience with treatment and how their resulting level of incapacitation impacted their ability to parent and as one father described, their attempts to “adapt and overcome.” At some point in their experience, all of the fathers described being too consumed with the tasks of treatment or too sick to do anything including parent their children in any form. They were in survival mode. As Bob stated, “It was survival. I was trying to make it through the next day.” The demands of the treatment schedule coupled with fatigue and pain presented an enormous barrier for the fathers.

Gordon: I feel bad because I feel useless and I lay around here all day by myself feeling sick, feeling sometimes nauseous, not all the time but sometimes, but just achy, pain, and it is hard to concentrate. It’s hard to even write an email. Definitely don’t want to read a book and even watching TV is sometimes annoying, or irritating cause you are trying to concentrate with your eyes. And it is hard to explain any of that why... just cause you are so focused on your pain you can’t do other things and its debilitating.

Bob: The whole role of the dad just went out the window. It was all about cancer. It was all about doctor appointments; it was all about getting to this thing and that thing and kind of forgetting about parenting. You know it was really hard to parent during that time because I was so tied up with my own stuff that I couldn’t. ... I really didn’t have anything to add to the family at that point because I had to take at that point. Instead of giving I had to take and that was, you know taking it on the chin. Dad doesn’t feel good today. He’s going to be in bed all day. ... The hardest part is when you feel horrible is trying to muster that feeling of trying to be a parent. Can I even be a parent right now? I just kind of had to shut down and just concentrate on healing. I just kind of felt like I detached from everybody for quite a while and I became this... focusing only on myself and healing myself. And there were times where there was a lot of irritability with the treatment and you’re just irritable. You’re just crabby and you don’t feel well and sometimes that really didn’t help the situation.

Bob recognized the loss that came with the time spent at treatment and the resulting physical incapacitation, “well there was a lot of things we didn’t get to do like go to the pool, and go hang out in the sun, go to the beach. There is a lot of things I just

couldn't do and it was like. God, I just missed the whole summer I mean my daughter's summer; my family's summer.”

Impact on Their Children/Family

“Because it had such an adverse impact to my body, I think it had an adverse impact to everybody else.”

It is now commonly expressed in the literature that a parent’s cancer diagnosis impacts the whole family. These fathers demonstrated a keen awareness that their experience with cancer impacted their entire family. As married fathers, each participant described their wives as their primary caregiver. The fathers expressed guilt that their diminished level of functioning and the busyness of treatments dramatically increased their wives’ workload or as Charlie described it meant their wives were “doing double duty.”

Gordon: Now I'm feeling guilty cause she has to come home and she has to do everything. You know there is already the stress of our marriage and the normal stress of raising a child. On top of the fact of you know her fears of when I'm gone. I try to say let's not worry about that now. Yeah, it's kind of tough. Your life is going to be a lot harder. I'm sorry.

As John expressed even his very young children who understand nothing about the disease feel the impact in their lives, “Yeah at their age, and to the extent that they were able to know, they cannot know up to 100%, they were not influenced up to 5%.” This section details the father’s perceptions of how their cancer diagnosis impacted their children both at home and in school. For example, three fathers reported that their children whose ages ranged from 7 – 12 years old had difficulty sleeping on their own after the diagnosis. Consequently all three of the fathers created flexible sleeping

arrangements to accommodate their children's needs until the children were able to sleep on their own.

Chris: When I came back from the surgery and what not. He wouldn't go to his own bed and he was about 12. We actually threw a bed next to our bed so he could sleep there. So he would hold my hand. After that we actually started sleep on the couch in the living room, just the two of us.

Four of the fathers noted that their children had difficulty in school. For example, one father reported that his teenage children became unsettled at school when several adults would repeatedly ask them how their dad was doing.

Tim: I remember them mentioning the people or some teacher stopped by today and said I'm so sorry about your dad. How's your dad doing? We're praying for you and this kind of thing. ...I think that may have shaken them a little, especially the daughters, the teachers and some of the people there were offering assistance and so in their minds that may have made them think hey is this more serious than I am getting at home cause there's these people I don't really know very well kinda offering their sympathies....

Difficulty with academic performance and social interactions at school were reported by two fathers who had sons that were 11 and 12 years old at the time the fathers were diagnosed.

Eric: And I think as it sunk in to him he got more withdrawn and he started to lose focus at school. And lose attention and getting into verbal arguments. With some kids were bullies but you know, whether it was teasing or they were bullying each other, but in any case. And then his grades started going down and he was getting A's and B's and now he is getting C's and D's.

Consequently, one of the fathers decided to remove his son from the traditional school and registered him in an online school. As Chris describes:

Chris: He got in trouble at school and I think a lot had to do with the fact that he was freaking out about his dad. He was stressed out you could tell. So that's partially why we put him on the computer school.

Another father reported that his cancer diagnosis had an opposite effect on his teenage son as he began his first year away from home in college. This father saw his son placing an inordinately high level of pressure on himself to be successful, to pick out the right major immediately and finish college quickly. Charlie described his son's distress.

Charlie: All of the sudden he was having all kinds of issues at school. Did I go to the right school? ...He was just going off the deep end that way and then he had really had issues at school trying to figure out a major and I said, "You're a freshman. What are you worried about for god's sakes?" But he just had it in his brain that he had to get through this and I think it was the cancer.

These fathers perceived that their feeling better impacted the family positively and helped them "heal." Several fathers noted that improvement in their level of functioning facilitated a return to some normal activities and as a result alleviated their children's fear that their father would die.

Bob: And she sees me healing so I think that's brighter for her. She's seeing me be brighter and having more energy. We get to do homework together and stuff now. So we'll sit down and we still argue. We still fight. She likes to push back. That's just the way she is. ...as I have felt better everything seems to have improved as far as time with kids. As you start to feel better than your mind set changes even more. So it starts to get to be that rolling snowball effect that the better you feel the better your attitude. The whole thing starts to snowball. Before you know it then everyone else around you starts to potentially heal too.

Eric: ...And this past year, this year, his grades started...Well towards the end of last year his grades started to come back up. ...But I think his emotions have stabilized a bit, dealing with me and seeing me get better I think that has helped him quite a bit. You know he sees me doing chores now that I couldn't do while I was in the middle of chemo. Shoveling snow and mowing the lawn, playing basketball again. I was actually taking him when he has days off so he can play with the guys I play with so he can see that I'm active so that's... The "are you going to die daddy" kind of goes away. But for the first few months it was like you know, every day.

The depth of the impact on the father's ability to parent depended primarily on how they were feeling physically, cognitively, and emotionally. As noted above, these fathers experienced numerous grueling side effects from the cancer as well as the treatments that left them feeling intense pain, nausea, and fatigue among other discomforts. The physical strains made it difficult for them to parent and presented an immense barrier with the potential to negatively influence the resilient process. Each father recognized that the stronger the impairment, the greater the negative impact on their ability to parent. These impairments combined with the time spent undergoing treatments and the numerous procedures and tests that are an inherent part of living with advanced cancer dramatically impacted the father's role in the family, the time they had to spend with their children, and their ideas about/or the way they planned for the future.

The figure below illustrates the impact of the fathers' level of impairment on their resilience process. As the father's indicated high levels of impairment interfered with their ability to parent and served as a barrier that tipped the balance toward feelings of despair (Figure 5).

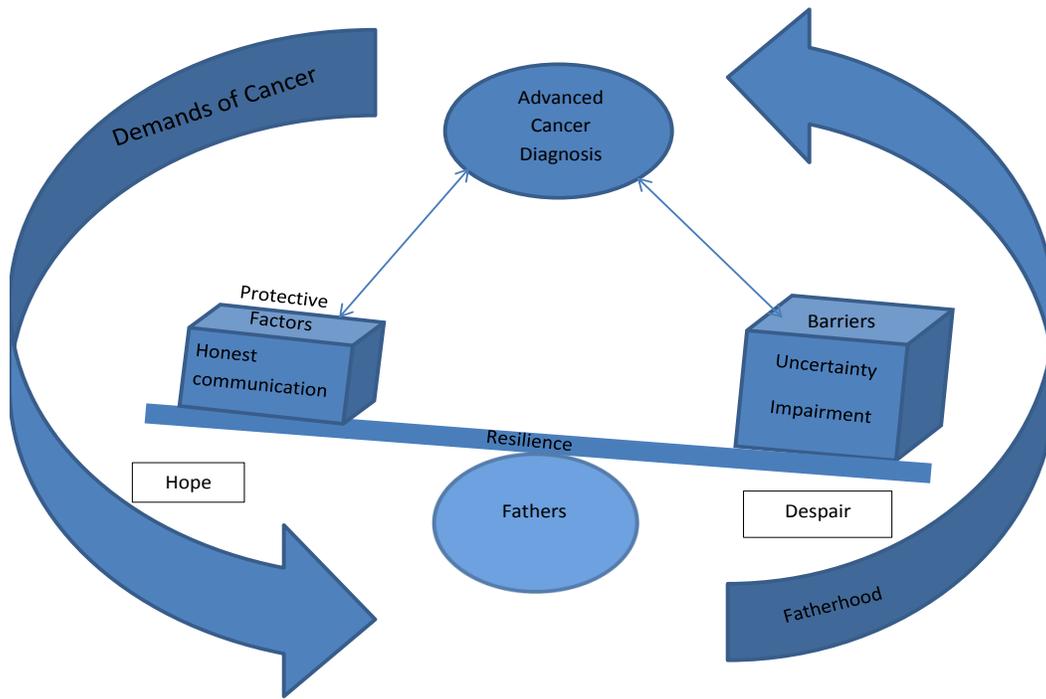


Figure 5. Higher levels of impairment as barriers to the resilience process

Father's Role in the Family/Role Changes

“But you know mostly that's me, disciplinarian, playmate, money maker, father figure.”

As one father succinctly captured in the above quote the participants in this study described their father role as consisting primarily of four functions: to be the provider, to teach and guide their children, to be their children's playmate, and their disciplinarian. The fathers' reported that these roles had been established early in their marital relationship and with few exceptions had not been altered. Each of these roles was impacted by their cancer diagnosis.

The provider. When asked to describe their role as a father in the family prior to being diagnosed with cancer, most participants identified their primary father role as the provider. They defined the provider role as working outside the home in order to meet their family's financial needs. As John describes, "I must take care of the shelter, pay my rent, I must take care of the food to feed them. Take care of their clothing..." There was one exception worth noting, the father who described himself as a stay-at-home dad. From the time his children were very young he had stayed home on a fulltime basis to care for them while his wife worked outside the home.

The other 10 participants defined their primary role as a father to be the "breadwinner" and provide financially for his family regardless of whether or not their wife was employed at the time of their diagnosis. This analysis suggests that this perception of father as provider was embedded in the participants understanding of societal expectations. This sense that the father's job is to provide for the family was very deeply ingrained in some of the men and they described this as a role that fit the needs of their family.

Bob: Well before cancer, I think I would always identify, like with most men, I think, you out to be the breadwinner. And it's your duty to provide. That's what I learned as a kid is the shelter, food and a place for everyone to live and you worked hard and that's really where I felt my role mostly was working, providing and then on weekends being around and being the dad. Not so much during the week.

Eric: not to be stereotypical but I always looked upon myself as the breadwinner, and I am. We decided my wife was an executive secretary doing pretty good in NY so we decided mutually that he would be best served by having a stay at home mom. It's worked out real well actually.

The effects of the cancer and the accompanying side effects along with the time spent in treatment jeopardized each of these fathers' ability to fulfill that role.

John: Working would be a problem, especially during that intensive time of treatment. There are days when you need to be in the hospital for two days at two day intervals and you spend more time there. So I don't know how many establishments that would like to retain somebody that won't come to work for two days, or three day intervals, one month or two months, it would be difficult.

For some it meant a temporary disruption in their ability to work full-time for others it meant the complete inability to work for many months and for others it meant losing their job or even their career altogether. For example, two fathers described how they would inevitably lose their job because their level of incapacitation left them unable to work.

Gordon: So I worked less than three months and I was already going off on medical leave. I worked three months. This whole year I have been off since January having treatments and stuff. ...I'm sure I'm going to get fired in January. Because the way the union contract is you can get medical leave for a year so I'm sure they'll fire me after that.

Charlie: Once I'm done with short term they can fire me. They can eliminate me from the payroll. I mean I don't blame them. I mean you're out nine months. That's a long time especially when you have somebody else backing your team up, making decisions.

The findings also suggest that these fathers who were no longer able to perform in their current career due to the effects of the disease experienced not only pervasive uncertainty but a sense of loss regarding their future.

Chris: That one I must confess hurt me. I was so close to getting my life back together and so I lost that temporary job. I was out of work and realized soon after that the driving was never... I couldn't drive. I had a choice to take the medication or not take the medication well that seizure hurt so I had to take the medication so I lost my job. I'm not a driver. What's going to happen now? ...That was bad. I

had to retake the medication and next thing now is what do I do now? And I don't know. I don't know.

Uncertainty about his future ability to perform his job also undergirds Charlie's experience. This father, who recently had to undergo a second brain surgery sat across from me with massive scars running across his scalp, swollen from steroids, and experienced such severe episodes of dizziness when we got up to leave it took several attempts to get him to the car, discussed his desire to try to work and the risks involved if he went back too soon.

Charlie: You sleep 3-4 hours a day, you know you go back to work too soon and you're not only going to hurt your health but just as importantly you'll probably get fired cause you're not going to be able to do your best. Sooner or later this isn't going to work out too well and then you're laid off and you got no health insurance.

Five men expressed feeling a societal pressure to be the provider. They were the primary source of income and in several homes they had been their family's only source of income for years. The loss of this role was very difficult for them as Charlie captures.

Charlie: I think more societal; fathers are to go out and hunt something and bring it in so you can eat. You know... the provider and being out of work is just *hard* [italics added]. Oh my god it is awful.

M: Why is that so hard? What do you think it is?

Charlie: Well I think for me it is because it has been my... That's who I am. We have been a single income family from the get go from the first time we had kids so.

One father described an easier adjustment to the loss of his role as provider. Two factors appeared to ease this adjustment. Firstly, he viewed this loss to be temporary, and

given his current positive response to his treatment, it was likely he could eventually return to work. Secondly, he is in a marital partnership where his wife also earned an income. Though he identified his father role as provider, he and his wife had shared a belief that it was necessary to both work in order to meet the family's financial needs. An understanding they held since the beginning of their marriage.

Mike: I would say nowadays mom's work too because you need a double income and so we always... we're always on the same page that nowadays you need to have two incomes in a family. Which you need to for the most part and when we did have kids, she was more of a night owl and I was kind of a ... I'm a very early person so we knew that would kinda work that way too. That we both had to be parents and that she would have to do her part and I would have to do my part.

The two fathers who were able to continue working had jobs that didn't require physical labor of any kind. In addition, they hadn't experienced any significant cognitive decline. Finally, they were employed at companies that accommodated their need to work from home periodically and the need to adjust their output considerably for those weeks when they were too incapacitated to function fully. This workplace flexibility enabled them to maintain their employment, income, and insurance and lessened the degree of financial hardship in comparison to the other fathers considerably.

Eric: it was very important to me to keep working and I took a medical leave for my first transplant. I took a medical leave of about three months. My second one I think I took two weeks of short term leave and that was it. I just worked. And I'm fortunate because my kind of job is not a physical job it's a mental job and so you know I have great respect for men and women who have what I have but like driving trucks or digging ditches. I mean I don't know how they do it. I'm assuming a lot of them you know, put in for disability and retire or something because I don't know how they could do it physically. There's no way. For me fortunately ...I can [do my job] from anywhere...

Disruption in the provider role: the financial impact. Financial insecurity can be detrimental to the process of forging resilience in the face of adversity (Walsh, 1996). Given that nearly 40% of people diagnosed with cancer fall below the federal poverty line during treatment (Yabroff et al., 2004), it is not surprising that most of these fathers spoke of the financial burden of living with advanced cancer.

Charlie: Which they do dry up, you know. I've been to the pharmacy three times, \$455 in three visits and that's the copay. You know I used to pay like \$10 bucks now its \$30, \$40, one of em is \$65 and I'm thrilled I got medical and I'm thrilled it got ... think of what it would be like if I didn't. But at the same time it does add up quickly.

Eric: I didn't realize, even though I have health insurance, it's not til you start paying out of pocket that you realize how much you pay out of pocket. So, that was a challenge and so by that being a challenge, I said, I need to work. I don't care if I'm undergoing chemo as long as I can mentally put one word in front of the other; I'm going to keep working. But a lot of it has to do with being the main breadwinner in the family.

The above quotes from Charlie and Eric are illustrative of the practical realities these 10 fathers faced when their provider role was disrupted as a result of their diagnosis. It's important to re-note that all of the men who participated in this study had insurance at the time of their diagnosis yet the financial costs of living with advanced cancer weighed heavily on them and compounded the uncertainty and loss they had experienced since being diagnosed with cancer.

Mark: I think for me from a male perspective the financial stuff is somewhat emotional to me so it's hard to explain as the provider. People might look at it and say that's not, why would that topic be an emotional topic? For me it probably over the years, been a pretty emotional topic to me personally. The one thing I feared the most was getting laid off from work and not being able to provide for my family and getting kicked out of our house and excess medical bills and you know and then somehow having my family structure go to pieces because I was a failure as a provider.

John: This kind of sickness or any kind of sickness is more disturbing when you don't have enough funds. ... When you have enough funds to take care of the bills make sure that your kids, your family are not disturbed in the shelter where they live, you are sure that you have food that they can eat, you are sure that when they dress and go out people will not laugh at them, then you know how to manage the stress, the pains, the discomfort. But when the fund is not there, it is complicated and compounds the problem. So there are so many things that can cause pain not only the injections, not only the chemotherapy treatment, not only the medicine you are taking, not only the kind of food you eat, not only the issue of not having enough strength that you are supposed to be having, lack of funds is immediate.

The fathers, who were too incapacitated to work, reported receiving Social Security Disability Insurance payments. For those seven fathers this was the family's only steady source of income. This disruption in their ability to fulfill their perceived role as the provider had multiple consequences for some of these fathers and their families. The financial burden meant they needed to make decisions about how to parcel out what limited funds they had. For Chris it meant having to choose between making house payments and having enough money to buy necessities. This financial strain eventually led to bankruptcy and put him at risk of losing his home.

Chris: But we did file for...bankruptcy. We had some credit card bills and what not which they got rid of those and that helped so we ... Obviously, I don't make as much money as before. That is the whole problem. Social Security is good but it is not an answer. So back to the are we going to lose the house eventually? I don't know. The financial impact is tough. Some places will help you out some places will not.

For Gene it meant adjusting the family's lifestyle, selling their large home on a lake at a financial loss and moving into a townhome with their son. Yet his ability to be flexible, plan, and adjust to these new financial realities reveals resilience. For Mike his loss of income meant his family lost their home. "My wife hadn't worked cause she was

taking care of me...and so we were almost broke... we did lose our house two years ago to foreclosure and then we ended up moving into an apartment.” Mike acknowledged the difficulty of this loss yet ultimately found their new home to be a better fit for his family as it was in a better school system and closer to his work.

Additionally, lack of income disrupted family activities for some fathers which contributed to their feelings of guilt about the impact the disease was having on the family. Scott described his sadness at not being able to afford taking his grandson to a fun activity.

Scott: Cause that made me feel so bad cause I couldn't, you know I can't take... there was the monster truck jam and Bryant the little one he really wanted to go and I definitely don't got the energy and I don't really have the money but so that I can't take him to go do this.

In the quote below Eric describes how he had to use savings he had allocated for his son's college education in order to meet out of pocket expenses related to his cancer treatment. This weighed heavily on him. He describes how this financial burden shapes his thoughts about future treatment decisions.

Eric: And one of the regrets I have of having cancer is that most of the out-of-pocket money that I had to use was money that I planned for his college savings and I can't do it. So I really regret that. ...I did tell that and everybody knows that if it did come back again, I'm not going to do treatment and just let nature take its course.

M: and how did you make the decision or what influences that choice?

Eric: One is again, concern for my family for them to have to go through this again and two, financial. You know, it would put them in a bind to keep going with the treatments. And just you know if my understanding is that I'm not going to get better, that I'm just going to fight until it doesn't grab me, then what's the use?

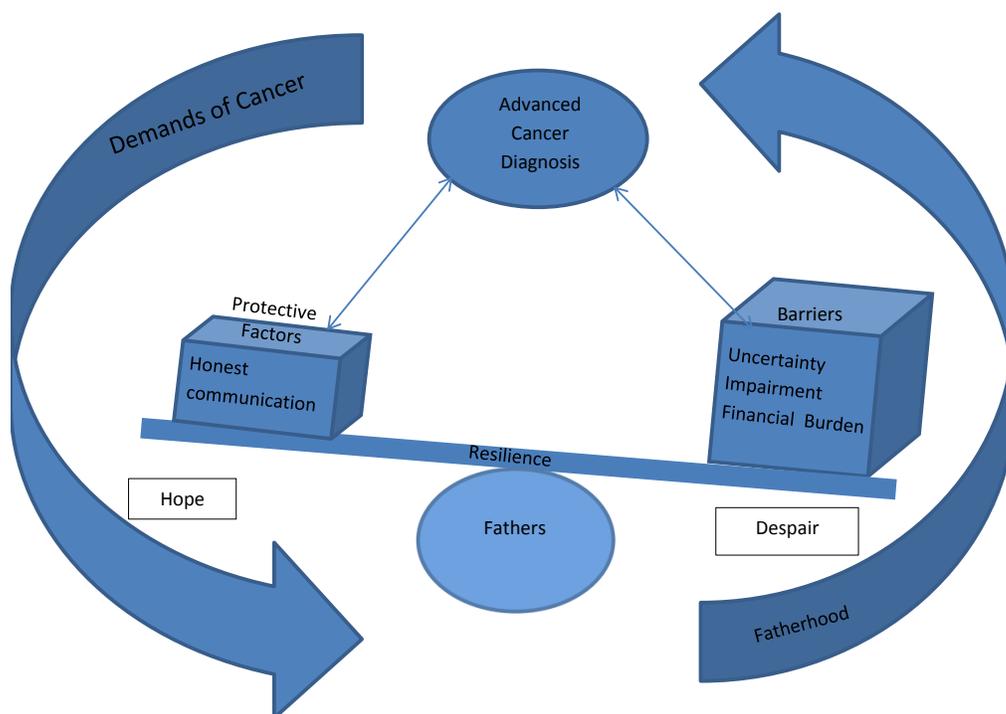


Figure 6. The weight of financial burdens in the resilience process

The fathers described the financial burdens piling up over time causing enormous worry and challenging the process of resilience (Figure 6). It is critical to note that for most of the fathers in this study, there would be no “completing” treatment. As a result, they hoped for the ability to return to work as they were able in order to meet the financial demands associated with the disease and overcome some of the financial hardship that occurred as a result of their inability to maintain their employment.

Provider role change to domestic. “But right now, I guess I look after the kid more and clean the house.” Chris’s experience shifting his primary role of provider to a more domestic function was shared by five of the fathers. The flexibility to shift their

primary role from provider to domestic/homemaker was somewhat dependent on their level of functioning, an indicator of resilience. Their health was still diminished and somewhat unpredictable leaving them unable to return to work outside the home. Yet they had opportunities where they felt less discomfort and fatigue and were able to take on some of the domestic responsibilities. The findings also reveal that this new domestic role gave these men a sense of purpose to their day and served as a protective factor in their resilience process (Figure 7).

Bob: Now that I'm feeling better my role as dad is like I said has been more laundry, cleaning up and making sure everyone's got food and cooking and the things I can do domestically. ... The last 3 or 4 months have been much better because I can get up in the morning and in the past I wasn't able to help much at all now I'm pretty much the breakfast guy, the dinner guy, the dishes guy, the laundry guy, so I pick up a lot of the things that... I try to help with [wife] in the house ... and it gives me a reason to get up in the morning to be with family.

Mike: I make a list every day of things I need to do every morning. I'll get the kids off to school and I'll sit down and I'll make a list and I have a whole bunch of things and my wife will sleep and by the time that she gets done I'll have the house cleaned and I'll have the laundry done. I'll have the dishes done and have a whole bunch of projects done and it's like, "you need to go take a rest" and I'm like, well let me finish my list first and then I'll do it.

The findings also suggest that these fathers' perceived this shift in role as temporary. Four of the participants were hopeful they could return to work when their current treatment regimen was completed and their level of functioning improved. Imbedded in this hope was a clear sense of uncertainty that challenged their resilience. As one father stated, "This is so hard to say cause I really don't know what's going to happen next with my role. My role's gonna probably go back a little bit in the direction of bread winner and being out more often."

A guide. This section introduces participants' conceptions of being a father and highlights their perceived father role as a guide to their children. This included imparting life lessons believed to be critical to their children's future as successful adults. In the following quote Mike succinctly describes this task, "I try to raise my kids with good standards and morals. I want my kids to be smart and know the difference between right and wrong." While being diagnosed with cancer didn't necessarily change these fathers' ability to perform this role, the analysis suggests these fathers experienced a pervasive sense of urgency embedded in their desire to prepare their children for their future. They wanted their children to learn to be responsible and be able to function well should their father die. Eric's quote below captures this sentiment shared by seven other fathers.

Eric: So but one thing that I have noticed myself, is that I tend to be hard on him. ...I've always been a little bit of a pusher. You know like education is important. I don't want any C's in my house and its either B's or A's. I've always been there with grades but even more so now cause of my condition, I'm more pushing for him to become more responsible. You know, sometimes I forget he's twelve. I forget that I was 12. I forget he's 12 and I think it is a little too much pressure. You know? I think some of it is my condition, my mortality that fact that I feel great now but I know that the storm might come and most likely it will come and so I want him to be prepared and so if he's a high schooler, get the best marks, get to college, get a full scholarship, you know, so I think I'm pushing him a little too much. ...but I kind of feel like I'm micromanaging him to make sure that he's ready when it happens.

A playmate. Another father role identified by seven participants was a description of themselves as a playmate for their children. Each of these fathers reported that their level of functioning impacted their ability to fulfill this role as they had in the past. For example, if the father experienced some cognitive impairment they reported being unable to focus enough to play board games or cards with their children. For others it was pain and fatigue that threatened this role. For example, Gordon describes

experiencing discomfort that was so extreme he was unable to tell a bedtime story to his child. “Usually we play a little bit ... and I’ll go in and tell him some stories that I make up...but lately, I’ve been too uncomfortable to even lay in bed with him.”

The fathers who described their play as physical in nature (e.g. roughhousing or playing catch) reported the fatigue and loss of strength meant they were no longer able to engage their children that way. Eric’s quote below captures this experience and describes recognition of their child’s need for play and an attempt to accommodate that need by encouraging time in this case with peers as other fathers described promoting time spent with siblings.

Eric: Because he's the only child in the house. I'm the play mate. You know going out and throwing the football or roughhousing and unfortunately I had to cut down much, there is no more roughhousing and he's a big boy um so it yeah, it did effect that. So what we try to do is arrange more play dates with friends from school...you know to get him out there with peers that kind of stuff.

A disciplinarian. Three men identified disciplinarian as one of their father roles. Here again the impairment they experienced influenced their capacity to fulfill this role in the manner they had prior to their diagnosis and treatment. Eric describes feeling a loss of credibility with his son, “...you're lying with tubes and you're trying to discipline your child and you know, he's thinking like really?” As did Charlie:

When you are home all day and you feel guilty of being home all day and not getting much done you tend to say, God who am I to talk? You feel less, at least I do, I feel less able to say things that I'm not doing myself, you know hypocritical things but so that's where I see that.

Time Spent with Children

“I loved spending my special time with him.”

Only one father, who described himself as a stay-at-home dad, reported seeing his primary father role as nurturing his children. However, it was often implied by the participants and often equated with spending time with their children. Living with cancer changed the amount and nature of the time fathers had to spend with their children and the father’s level of functioning again was the primary influential factor. All of the fathers in the study demonstrated a determination to spend time with their children despite their pain or fatigue.

Mike: ...at times I was the only one there which happened a few times and I knew the kids wanted to do something or were really bored or getting on each other’s nerves I would get up no matter how I felt. No matter how I felt. I wasn't feeling good at all and they understood that they still needed to be good. But I would just get up and do it and we would go out and do something. I push myself to the limits sometimes which sometimes is... I just felt like I had to do it. I'm the dad and I need to take care of my kids.

John: So now for the first time my children did not see me for almost one week cause when I was in the hospital. When I got my discharge... when I entered the house they ran to jump on my body. I said, “God give me the strength to carry these children.” And I am happy I can have the experience of maybe the pains in my body because I’m alive. That joy of carrying them again in this house made me to have the strength to carry them so I grabbed them and we prayed and thanked god for seeing their father and seeing each other again in this house. I showed them love the way I could at that moment.

For some fathers, their change from provider to a primarily domestic role meant they had more time with their children for example, being available to help with homework. Once again, level of impairment had a significant impact on how this time was spent as Gordon’s quote below captures; this was a delicate balance that depended on how he was feeling.

Gordon: So right now, being so sick, as ironic as it is, I get to spend a lot more time with him. Not lately, just cause I have been more sick. When he was younger we took him out of daycare at that point and he was basically home with me every day. Family would come and help out from time to time. But eventually we put him back in day care but you know working as a nurse I would go 3-4 days a week without seeing him. He'd be asleep by the time I'd leave and he'd be asleep when I got home. ...I want to sit down and have dinner at the table. It doesn't always work that way. Sometimes it's eating on the run. I liked it better when I took him to school because then we would sit down and we would have breakfast together even if it took an hour. Lately I have been more sick so she has had to take him and pick him up. It's easier on me but I loved spending my special time with him. Hopefully, I'll get it back.

Dreams for The Future

“We wanted to have more of a family but there is no chance of doing that.”

For the fathers in this study being diagnosed with an advanced life-threatening disease and the uncertainty and loss woven throughout that experience impacted their dreams and goals for the future. Surviving until their children reached major life events permeated the interviews of all the participants. The desire to see their children graduate from high school was particularly strong and was specifically noted by all of the father with two exceptions, the two fathers who had children under the age of 4 years old.

Tim: When I was younger I had three goals, simple goals. I want to see my three kids graduate from high school, college and walk two girls down the aisle. That's all. And the thought that I would never attain one of those goals was heartbreaking. ...so I have attended one high school graduation and another one next spring. Hopefully, I will attain two.

These financial and physical losses combined with the uncertainty of the outcome made it difficult to make plans or even coordinate family life.

Bob: And we don't know because we are in mystery right now. We are still in the waiting stage for tests at the end of this month and then we have a new plan. The new plan will help determine you know how we move forward as a family.

The father's decreased level of functioning and dire prognosis meant having to let go of some dreams. At times when the fathers spoke of these lost dreams for their future the emotional pain was palpable as seen in Gordon's quote below.

Gordon: Then of course we wanted to have more of a family but there is no chance of doing that. Whether or not I can, we don't even know but we don't want to take the chances and now the likelihood that I'll be around is lower cause its stage four and once its spread there is no way to take it out. You are on chemo for the rest of your life or something. So that's kind of where we are stuck.

However for six fathers the uncertainty inspired them to plan family trips. They spoke of trips they had taken or were planning to take soon. These are trips that would have normally been delayed until the children were older or they felt more financially secure but the cancer diagnosis spurred them to take the time and spend the money now. The findings suggest the desire to plan a family trip was influenced by their keener sense of mortality and the knowledge that life is uncertain and that they may not have many opportunities in the future. It was also influenced by their desire to create memories with their children. Yet uncertainty was woven into the descriptions of their plans as Bob's quote below describes.

Bob: You know we really want to do something as a family and get out of here. Just say, let's just leave cancer behind and ...all our worries and go have fun somewhere. We've never done a really good winter beach break and just get out of here and I think we all deserve it. We have been crazy for the last nine months. So with my health starting to improve and chemo being over I have a feeling I'll be able to tolerate a trip. My biggest fear is how I am going to feel. If I feel like crap, am I even going to be able to make it on the plane? For eight hours to get to Hawaii or wherever. That's been some of the challenges - the wonder can I do it? Am I gonna be okay to do it?

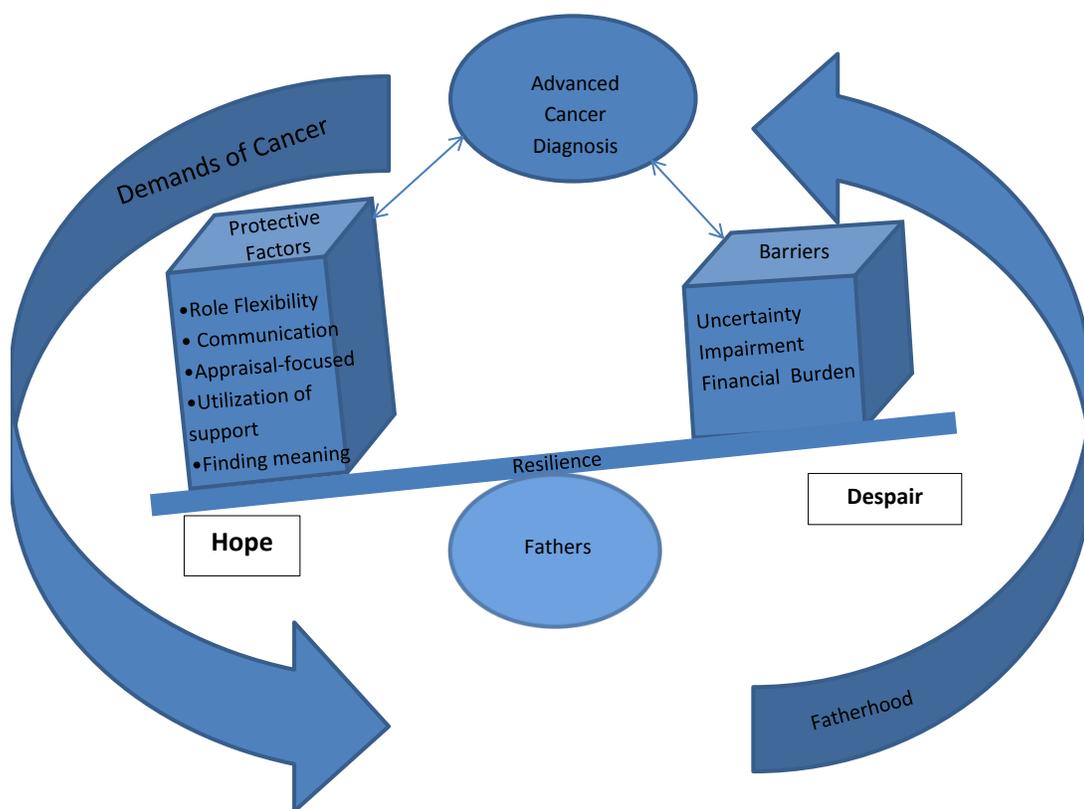


Figure 7. Protective factors as a counterbalance in the resilience process

As they move through their cancer experience, the fathers described drawing on various protective factors that served as a counterbalance to the accumulating barriers. The findings indicate in addition to open and honest communication with their children, the fathers discovered supportive resources that were available to them which helped diminish their feelings of despair. In addition they were able to find meaning in the experience enabling them to begin to make sense of what was happening to them and how they have learned from it. The following two sections describe the fathers' experiences with various types of support and describe the meaning made so far offering an illustration of how these pathways shaped their resilience process toward hope.

Support

The availability of multifaceted support and the fathers' outreach to use them are essential for building resilience in the face of the extraordinary challenge of fathering through advanced cancer. Every participant described various supportive resources upon which they relied as a result of their diagnosis. This section focuses on participants' experiences with seeking and receiving support as they navigated their cancer experience as a father. Analysis revealed three primary themes related to the fathers experience with support which included: difficulties asking for and accepting help, recognizing the need for help, and type of support which includes both informal and formal resources.

Difficulty Asking for and Accepting Help **“It was tough to reach out for help.”**

The ability to seek help has been found to support resilience (Walsh, 2006). During discussions of support eight fathers reported they found it difficult to ask for and accept help. The findings suggest that this difficulty accepting help stemmed from a strong discomfort admitting their own vulnerability or revealing that vulnerability to their family, community or in the workplace.

Mike: I don't like being vulnerable. Having everybody, “oh we gotta help Mike, we gotta help Mike.” I always do everything myself. I fix everything myself. No matter what I do, I always do it myself. I don't like help. ...I don't let other people see me vulnerable. I've been doing this for two years so I've kind of gotten used to it a little bit but I still don't like it. I don't like being sick. I don't like having some of the people do things that I know I can do myself. Like I would do all this stuff myself. ...I never used to want to have help from anybody. I was very stubborn.

Eric: That was hard for me. My wife not so much, but for me it was tough to reach out for help. If it was up to me I wouldn't have asked. I would have gone on even though I was physically unable and shoveled but she went and talked to

some neighbors and asked them if they would do some and mow the lawn for a while. ...I would have never done that. I still wouldn't do it.

The father's linked this aversion to revealing vulnerability with their father role as a provider and with their perceptions of the societal expectations of being a man. The appearance of vulnerability wasn't seen as socially acceptable nor did it equate with being successful. These conceptions intertwined to act as a barrier in the resilience process as it interfered with their help-seeking behaviors.

Mark: I think as a ... again my personality and not to be chauvinistic but as a provider for the family... it's been humbling for all the support that we've gotten all the help. it's been great but it's also been...there's a certain part of me that says "I don't want any help" "I don't need help" so it's kind of struggling with accepting... definitely appreciative of everything but part of me just wants to say "we don't need any" that's been definitely a learning experience for me... definitely very difficult at times to accept it. You know I think it's probably the provider mentality. For so long I was the main provider and you know from a financial perspective I guess and just from a fact that my... I guess some if it may be ego too and the fact that you know that I can take care of myself and I've been successful and um you know. I was pretty in shape and athletic and doing all this stuff before I got diagnosed and have that kind of invincible type attitude and then have something like this happen and you know realize that um maybe we needed some help. It was really difficult for me so. It's great because we have those types of friends but it was definitely one of the harder things to accept this from my view from being a provider to the family.

Tim: I think that it is probably hard for us men to reveal that kind of vulnerability that yeah I did get cancer and I got knocked on my butt but I'm here now and I think there is some reason we don't consider that a badge of honor or courage

Eric: What is it? It's that hunter thing. It's the macho... Yeah, the hunter, macho-loner, self-sufficient, independent and it would be a sign of weakness if I need somebody even if I'm on my deathbed. I don't know where it comes from. I think men are just, some men, I can't stereo-type, I think some men are just wired like that. I think there are those expectations that, yeah. Man being strong, being the breadwinner, being independent, don't wanna be nobody's fool, you know what I mean? ...So it's a little bit of that and it's hard for me to let go I think it's more almost just embarrassment that you can't take care of yourself. It might be a little bit of that. A little bit of shame or embarrassment and I don't know where that comes from but it's like you're not a man if you don't take care of things yourself.

Two men discussed the difficulty of needing help at work. Here there was also a practical motivation to not appear vulnerable in order to protect their job and consequently their father role as provider. Mark offers his example.

Mark: it's difficult again to accept that sort of thing in a work situation as well because you try and act like I'm fine I can do this and you have to be a bit more guarded so um it's difficult. There are people at work, and not only people I work with but my clients that get this, that I don't necessarily always feel comfortable having them know that detail because I sometimes I feel from a work perspective that people make decisions that may take into account my situation. Should we have Mark work on this? He's not healthy and a year from now ... should we have someone else work on this? That is a concern I have. It helps that they see that it has been manageable. I think once it's not manageable it's not manageable then maybe I won't care as much but I think there hasn't been... I haven't seen a big exodus of my clients because of this but it's ongoing when I'm talking to them or they're asking questions about how I'm doing is there a work related aspect? Something I have to deal with.

Recognizing the Need for Help

“Get over it. You can't do it yourself.”

Though it wasn't easy for the fathers to accept, eventually all of the participants recognized they needed some form of support. Bob described this realization as “taking it on the chin” suggesting that needing help was somehow a sign of defeat on his part.

Bob: I really didn't have anything to add to the family at that point because I had to take at that point. Instead of giving I had to take and that was, you know taking it on the chin. ...you know I'm the one who is all you know, got whacked here pretty hard and now I'm knocked out and I need to take from the family. I need support. So I needed help.

Several men suggested it was their wife who helped them understand and accept their need for help. Mike captures this, “She [his wife] helps me to say hey, you need to accept that you need help and that's been very helpful helping me realize that I need help that I can't do everything myself.” Scott had a sense of humor as he described his wife's

skill at creating a safe context for him to be vulnerable and accept help while protecting his sense of masculinity.

Scott: But this woman, I don't know how she did it but she rallied got our finances and there is only so much she can do so you know, and still did not emasculate or however you say it. She didn't cut my goodies off, you know. And as a matter of fact, she was saying I was still good looking. She was trying to keep my self-esteem up.

Several fathers shared that while accepting help for them was difficult they readily accepted the idea that their children would need help given the presence of this life-threatening disease in their lives. For example, Tim recognized immediately that he would need help fulfilling his commitment as a father to his children especially if he did not survive. In the following quote Tim describes how he planned to find help for his children:

Tim: I have a diagnosis. I have cancer. Now we know so we can go forward. I remember on the ride home clearly penning a letter in my head to about 5 guys ...that if I die what I expected them to do for my kids and for my wife. ... That I would ask my men friends to you know ...be male influences in my kids' life. I went to that place immediately. ...I physically knew I was dying and so I'm going to have this surgery and they say I'm going to have chemotherapy and this is not looking good. Um I don't know how much longer I have. I need help and this is how I will get help. I will send these guys an email or a letter and get these guys on board right now.

Interestingly, he specifically wanted this help to come from male friends so they could provide a "male influence" both for his son and his daughters. In his family, as the only stay-at-home dad in this cohort, this male influence was primarily nurturing and valued full engagement with the kids. He stated he had not written that letter yet as he

was currently in remission and life had stabilized. He didn't feel it was necessary at this time but indicated he would follow through if the cancer recurred.

Though most of these fathers described deep concern for their children's well-being, they reported it was their wives who first recognized their children needed help and sought out supportive opportunities for their children. Charlie and Eric describe this experience.

Charlie: [his wife] was the one who saw we needed help. and I think it is because, it's a couple of things, I think it is because of the nurturing, the natural nurturing that a mother and also I think she is just brighter when it comes to support. You know for whatever reason, she just knows it's needed versus me not seeing it until something happens. But you know she went right out and she said, "You know I got to find a group for these kids." The first thing. I don't know if I would have done that. I hope I would have. But not right out of the shoot. It was within a week that she had it set up...

Eric: Now I was gung-ho when [his wife] found this out about this organization and said we should do this. If it is going to help [our son], well yeah so but I wouldn't have been the one who was looking for this program.

Supportive Strategies

"You need a support group - whatever it looks like."

This section highlights the supportive strategies employed by or considered by the fathers in this study. Throughout the interviews, numerous topics were discussed that focused on strategies these participants employed to meet and manage the challenges of fathering through advanced cancer. These strategies fall into two broad categories, informal and formal. The informal support strategies identified by the participants consisted of appraisal-focused skills, spiritual beliefs and practices, as well as social resources that included family, friends, neighbors, and work colleagues. The formal

support strategies identified included in-person and online support communities, as well as financial support from public agencies and private organizations.

Informal support. The fathers identified various types of support they either considered or utilized as they fathered through cancer. These included appraisal-focused strategies that enabled them to reshape the way they think about and understand their disease such as positive self-talk, compartmentalization and humor.

Constructive self-talk. Constructive self-talk is the code chosen to describe a primarily internal dialogue the fathers used as a cognitive technique to manage negative thoughts. While this strategy could be considered maladaptive if the participants were attempting to deceive themselves, as noted above these fathers were well aware of the seriousness of their circumstance. The findings suggest that all of the fathers in the study used a form of constructive self-talk throughout their cancer experience as an adaptive strategy to manage their distress. Several fathers described drawing upon this technique when they were alone. For example, participants described experiencing especially low moments in the middle of the night and identified self-talk to be the primary technique used to manage their distress. Several fathers reported telling themselves to “just get over it,” or that “I just gotta do this” or “I can do this.” Several fathers used comparisons with others as a way to “talk themselves out of” moments of despair, for example referring to children with cancer as a significantly more challenging situation.

Mike and John both used forms of self-talk to address their fears of death. In these two cases their self-talk was not an attempt to be deceptive. Each of these men were given relatively good prognoses despite their advanced cancer diagnoses. At this point in

their cancer experience the cancer is responding to the treatments and both have medically-based rational to hope for remission or even cure.

Mike: it really does affect our sleeping schedule and your brain doesn't stop moving and doesn't stop working ever. You're always thinking about something. Whether good or bad. ... When I first got sick. I would always, I kind of always said, "I'm going to make it through this. There's no way around it. I'm getting through it." ... You just need to say, "I'm going to get through it. I'm going to move on and it's just a bump in the road and you learn as you go." You just need to say, "I'm going to get through it."

John: Sickness you visitor, one day you must go and you must be alive. So that pain of thinking that I must die in the next one month or one year or three years is not there. When you begin to focus more on deathish area you think that death message from time to time even when that death message comes and says John you are going to die, I said "No!" [He spoke loudly with emphasis]. I am not going to die. I'm not going to die. Death can come when it comes but it is not now. So when you know for certain that it is not time for you to die you overcome the pain of thinking about your dying very soon.

Compartmentalization. The fathers described the process of waiting as being potentially stressful in the context of living with cancer while parenting children. Several men described compartmentalizing their concerns using phrases like "not dwelling on it now" or "we'll take it as we go" or "if it gets bad, we'll deal with it then."

Compartmentalizing their concerns about future tests and scans was one strategy the fathers identified that enabled them to maintain their focus on the present.

Mark: so if I'm feeling good and I don't have a scan for three months just not worrying about what's going to happen 4-5 months from now but just enjoying the present and really try to focus on parenting the kids that way rather than saying "well you know dad's got a scan in three months and it could be bad" and whatever...

Humor. Humor in the face of a life-threatening disease can be a very effective strategy to reduce distress in the face of adversity. Each the fathers in this study identified and displayed their ability to use humor as a way to manage the strains of fathering with

advanced cancer. For example Bob used humor as one way to manage his frustrations with the ups and downs that are inherent in a cancer experience, “I like to say I coined this phrase, *there's always a butt with cancer*. So it’s like, this is great butt... we found a little something over here. Or this is great butt...it’s like okay enough butts.”

Several of the men used humor as a strategy to enable them to speak about their potential death. For example, Charlie displayed his use of humor when he described his thoughts about planning his own funeral.

Charlie: I'm teeter-tottering between planning a funeral just to have it so my kids don't have to deal with it and my wife doesn't have to deal with it. Or just letting whatever happens happen. You know cause it's really not for me anymore once I'm dead. It's really for the family so. What do you want to do? Put me in the back yard. It doesn't matter [he laughs].

For some fathers, the humor had a relational component drawing family members into the laughter. Tim spoke about the ability of his children to joke about his disease and the resulting decrease in his cognitive functioning as a result of the strains of treatment.

Tim: you know they knew that I could not mentally lock in like I had in the past so they were really aware of it and tolerant and the kids kind of joke about it...We did use humor probably sometimes kind of macabre humor. ..So yeah we did use some humor. We joked about back to Christmas my son gave me a little bottle of colon cleaner hot sauce. So we found we really did have to laugh a lot.

Eric described an ongoing joke between him and his wife about timing his death so that it can be most beneficial to the family.

Eric: I'm not a jokester but I do have a ... my wife calls it a dry sense of humor. Yeah, you gotta laugh ... my wife and I have a little running joke ...I jokingly tell my wife you know, “it’s okay if you put a little banana peel down a flight of stairs or you know the garage door comes on down but make sure you do it at the right time.”

Several fathers used humor to describe some of the simply absurd aspects of

living with and being treated for cancer. For example, when a dermatologist took several months to link the horrible rash on one father's body, which appeared a few weeks into his chemotherapy, to be a result of that chemotherapy.

Other times fathers found humor in the type of support they received. For example, needing to borrow a neighbor's refrigerator to store all the food the neighbors were bringing to the house or the friend that comes over to cook and destroys the kitchen in the process. In the quote below Scott illustrates the humorous aspects of support from his young children:

Scott: So I start walking down the sidewalk and I look to my left and I look to my right and there's one granddaughter and there's another granddaughter and I look back and there's another granddaughter and the [his grandson] is on the side and I said, What are you guys doing? Well, nana told us to keep an eye on you as you take a walk.

Spiritual resources. Spiritual resources are a common strategy people draw upon for strength and comfort when faced with a life-threatening disease (Balboni et al., 2007). For six of these fathers their spiritual beliefs, practices, or faith communities were identified as key sources of support. For some that meant praying or reading the Bible at times of great strain. Others drew strength from congregational support or individual meetings with a faith leader such as a pastor or priest. Eric's faith provides context to his suffering.

Eric: One would be my faith; you know one of the principals of Catholicism is suffering. If you don't suffer you're not really alive. You know suffering is part of life. It's not going to be all sunshine or all cloudy. It's going to be partly sunny and partly cloudy.

John describes the pivotal role his Christian faith plays in his ability to manage his feelings of fears and uncertainty after being diagnosed:

John: I look at the situation, yes I am in a critical condition but the truth is this - that god handles every situation and is in control ...that is faith. Humanly speaking it wasn't anything to welcome the news but when I remembered again and again, it was more than every second, more than every second that God is in control. From my religious background the Bible said that faith without work is dead. When I say that God is in control I still strongly believe that God gives people divine wisdom to know what to bring together to form the medicine that will heal a particular disease. So if the doctors say that from their knowledge from their experience of this when you take it and use the drugs, the medicine that they ask you to use - yes I'm using it. I'm not believing that without god this medicine will work better but with god's grace this medicine will work. Without this faith and work combined together to get a good result of what they are looking for so that has by god's grace helped.

Other fathers mentioned relying on meditation or imagery as accompanying their spiritual beliefs. Two father mentioned choosing specific images on which to incorporate into their experience. Charlie, for example, reported finding comfort from praying as well as from buffalo imagery.

Charlie: So I decided to get like a totem, I read a book that talked about how important it is to get the body's defenses going along with the medical. So I decided to go with an animal. So my choice was the buffalo because I just love buffalos...we settled on the buffalo and then my family went out and bought me a hide. You know a true buffalo hide that I am supposed to wrap myself in...wrap myself while I watch television but yeah so I would wrap myself up in it and when I went to radiation treatment I would visualize buffalo running through my veins and hitting the tumors with their powerful heads, shoulders and such. So that's a way that I kind of help I pray and I think of the buffalo.

Charlie described the image of the buffalo as a source of comfort as well as a way to focus his energy on healing. In addition he felt his family also embraced the image. He felt this shared inspiration of the buffalo helped include his children in his experience and gave them something on which to hold.

Charlie: So that's a way that I kind of help and that is something that my son, the oldest, could really relate to. ...my oldest [son] and my middle [son] were thrilled

with it and really liked it and it was kind of hip. So everything became buffalo, buffalo, buffalo, buffalo. Buffalo nickels that people gave me. I got a lot of necklaces with buffalo nickels on them. So all in all that's been good.

At numerous times throughout the interviews, many fathers referred to the middle of the night, when it was dark and they were alone to be especially difficult to face. The positive self-talk, praying and imagery were reported as affective in staving off intrusive thoughts and managing distress. In these moments of isolation and despair, Gordon found a conversation with the spirit of an old friend to be comforting.

Gordon: ...an old friend of mine had died from pancreatic cancer and we had both been [coffee shop] managers back in the day in San Francisco. So I think about him a lot. ...So I kind of summoned him and talked to him a bit last night when I was having a lot of pain. I was laying on the couch for a while having trouble sleeping I was in so much pain and so I kind of called him up, my old friend Phil. I can still hear his voice and just talking to him like we are now but hearing his voice was really neat. I guess comforting.

Family. “Friends and family were very, very, key.” As Chris’s quote succinctly captures, family social support networks were critical sources of support upon which all of these fathers relied heavily. The most prominent supportive relationship identified by each father was his spouse. Not only did the wives provide emotional and practical support such as driving them to treatments or caring for their children, a number of men described times when their wives advocated for them with various medical or insurance systems when the fathers were too sick to do it themselves. Scott described his wife this way, “She’s my little pit-bull I tell my doctor. She’s tenacious. This support did not go unnoticed as several fathers noted, “I can’t imagine the people who do it without a spouse.”

Several participants indicated they drew strength from their children's support. The fathers described various ways their children provided support such as massaging their feet, bringing them food, providing humor to lighten their mood, or just sitting with them and watching a show on television. Father's with younger children described many tender moments when their children would just sit with them as illustrated in Scott's example below:

Scott: they tugged on my heartstrings so much cause there were times when I would wake up and I would find one child in there and then go back to sleep and wake up and now there are two kids and a neighbor who we had befriended would come in ...then I'd wake up and all the kids are in the room but so quiet. I'd say, "What are you guys doing?" Well, we're just sitting in here. We are all doing our homework."

Outside the immediate nuclear family, extended kin networks were invaluable as well especially when it came to helping care for younger children. While not all of the fathers had extended family nearby, those who did found their willingness to help with the children to be crucial and deeply appreciated.

Mike: She [his wife] has two sisters, a younger and an older and I have two brothers, a younger and an older and they have all done their part to take the kids every so often. Take them over night. My parents take the kids a lot overnight and then my dad takes them, like we'll drop them off on a Saturday night and my dad will take them to church on Sunday morning. ...My younger brother is the one... he can tell when we're talking on the phone if I'm having a stressed out day. He'll just pop in and say, "Okay, I'm taking the kids. Get out of here."

Community. Social networks that stretched beyond their identified family provided another source of support for all of the fathers in this study and revealed a connectedness each father had to a larger community including friends, neighbors, and colleagues. The fathers described the myriad practical support their community offered

over time such as bringing food, mowing the lawn or shoveling the driveway. Several fathers noted that friends and neighbors were a key source they relied upon to care for their children. This support included driving them to activities or caring for them for extended periods of time as Gene describes the experience of his 12 year old son, “He stayed with a family friend of ours... for several weeks while I was going through my second bone marrow biopsy. It was fun for him. She had a son his age too.”

Interestingly, when we discussed the topic of support not one father mentioned specifically receiving emotional support from friends, neighbors, or colleagues.

Emotional support was implied in various ways such as descriptions of friends spending time with them but that rarely included talking about their cancer experience beyond physical terms.

Tim: It was nice to have a friend. Did we really talk about cancer? That's, you know he would ask how you are feeling and I would tell him sincerely how I was feeling, physically. I don't know that we every really got into any emotional conversations. About, you know, where do you think this is going Tim or what if this doesn't work out? I don't think we ever could do that. ... I don't feel that was a void and maybe I don't allow myself to feel the void. I don't know. I'd have to think about that.

Bob was a bit more explicit in the quote below yet it is interesting to note that he immediately follows with an example of financial support:

A couple of my really close high school friends have been nothing but completely there. They have been maybe three of them that have been really strong and two of them that have been stronger. And the two of them actually came up with the idea to have a benefit account for us and to solicit money for people to support us. And one couple even went so far as to buy us a new garage door.

Financial support from friends, neighbors, and colleagues was identified by seven

of the participants including Bob. This financial support took a variety of forms from, donating vacation days and frequent flyer miles to direct monetary donations. Many fathers described this support as being somewhat unexpected and deeply valued. Eric describes how this experience broadened his perception of who was in his circle of support and how receiving this support transformed his relationships with his colleagues.

Eric: My colleagues have been unbelievable. They, when I was in the second transplant. They came to my house, my wife requested, so they moved furniture so she was able to clean and vacuum and then put the furniture back. It sterilized the house and two of them, about six months after I was diagnosed; they put together a benefit for me which helped quite a bit with the out-of-pocket expenses. ...But you know they helped me cause you know I don't have family here. So it's kind of tough to have...our inner circle, there's nothing in there but us; there is nobody else except a few friends here and there. So it was very nice to see people, I would call them more associates than friends get together and do that so they have become more friends than associates.

A few fathers noted that at times the support, while appreciated, was not always the type of support they needed or that accepting the support created work for them. Sometimes it was as simple as getting too much food and having nowhere to store it, an experience noted by many cancer survivors in my practice. Several of the fathers expressed feeling overwhelmed by all the advice about books to read, or treatments to try, or people they should call that were not necessarily relevant to their needs or it was offered at a time they were unable to use it.

Chris: Right away people came up to me; people gave us so much food that you have no room for it. You want to say can you bring it to us in a couple of months? They were very helpful and so many people said, it was actually too much, people wanted to help but couldn't. So many people said you gotta call this person or this person and deal with this and after a while I just didn't bother.

Mark: I had lots of different financial advice from people that weren't necessarily in my same shoes as far as and maybe even went overboard to some extent in some cases you know more or less like you gotta do this because you're gonna die next month.

Formal support. All of the fathers in this study received some type of formal support as well. This support was obtained from both private and public spheres.

Public. Public support was limited to receiving social security disability. Eight of the eleven fathers qualified for SSDI and were receiving it at the time of this interview. For these men, this public support was their only source of income as the demands of the disease coupled with the responsibility of parenting limited their wives ability to work as well. While these funds eased the financial burdens they felt as providers, it was rarely enough money to meet all of the needs of a family with growing children. This created a predicament for several fathers who were independent contractors. For example one father, who had been living with cancer for nearly two years, described having brief windows of opportunity where he felt well enough to work. Yet, the disability benefits he was receiving didn't allow for the kind of work flexibility he needed without risking the loss of those benefits. Chris notes a similar experience.

Chris: I said well, the problem is I'm getting social security and if I take a part-time job at UPS, which I may not have a choice, I'll lose the Social Security and Social Security is paying me more than [his employer] so I'm kind of delaying and pushing it off sooner or later, I gotta go back to work. Hopefully something will turn up like what I was doing before but right now last time I talked with them they said all we can do is give you something part time. Hopefully that'll change. If that's the case and I do a part time job then I lose my Social Security, we might lose the house. I don't know so I'm not... I just told my neighbor yesterday I don't know if I can stay here. But yeah, if I do get a part time job there I'm going to have to get a part time job somewhere else. Cause I can't work part time and.

Private. Private formal supportive resources utilized by the fathers included both psychosocial and financial resources. For example seven fathers described using the online support community CaringBridge to create a personal website. This personal website was then used to communicate information about their cancer experience with their family, friends, and community. This allowed their support network to keep informed of any changes, successes, or challenges that occurred and enabled those readers to post messages of encouragement or support. The participants described using this site to also organize practical support such as rides to treatment or food deliveries as well as notifying their readers of the need for financial support. Several fathers made use of the sites to provide information about special accounts that had been set up or fundraisers that were being held in their honor. While several fathers posted messages on their site, it was often managed by their wives.

Mark: my wife does a pretty good job keeping the CaringBridge site up to date and so everybody kind of subscribes to that and they get real-time updates about what is going on so everybody stays in the loop. And that's something that is great for me. My friends will ask me and they'll know I had surgery. They ask how're you feeling and is there anything we can do? That sort of thing you know. Where are you at and what's next? Luckily they can get through email more or less and it helps me because and my wife so we don't have to retell and relive the same thing 50 times.

Local community organizations were also a critical source of support for this group of fathers for both financial and psychosocial support. For example, eight fathers reported receiving financial grants that enabled them to pay rent and other household expenses. Some described receiving free tickets for the family to attend sporting events or

other family friendly activities. Two fathers reported having food delivered to their homes while they were in treatment.

Local community organizations and hospitals offered opportunities for these participants to seek psychosocial support either as an individual, for their kids, or for the whole family. Support groups were the primary vehicle available. Some of the fathers in this study were conflicted about attending support groups. While they acknowledge that others might find them beneficial, they were reluctant to attend. A discomfort with exposing their own emotional vulnerability as well as being around other vulnerable people influenced the decisions about seeking help for some fathers. The findings suggest their reluctance to attend was connected in part to their perception of men as strong and independent and not needing help.

Mike: There are support groups here and my wife is trying to get me into them. I just...it's just not me. I mean I'm sure there's many fathers that would like that but my wife likes going to support groups every so often but she's more ...takes stuff in like that. That's just not me. I just don't. I'm not one to sit in with a bunch of guys and just talk about it. I've just never been that way. I think a lot of guys are like that. I mean there are opportunities here at the BMT clinic and my wife has taken opportunities to go do that and she says I really think you... and push me but I'm like that is not me. I don't do that.

Tim: And I remember the nurse suggesting you want to come to group meetings? I remember thinking at the time; why in the hell would I want to do that? Umm, it just wasn't interesting to me. ...you know we men communicate so differently. We're such different and loner animals in some way and I think it is more difficult for us to build those close relationships. Would I have confided in somebody? A guy that I didn't know? I don't know that I would have. I think women are much more likely to do that. So I don't know. Like I said, I didn't even go to the group meetings. I'm going to fight my own fight and do it my way.

In addition to not wanting to be vulnerable in an intimate group setting, Eric described a need to not be defined by his diagnosis.

Eric: I'm not a group person and I know myself. I'm comfortable with that and I know it's a great benefit to a lot of people that I've met. ...I'm not a support person or maybe I'm resisting not being a support person Cause again that vulnerability thing... I'm going to share this with other people? The other thing is I don't want to let my cancer define me. And so I don't want to go to support groups every month and once again bring the focus back to the cancer. That's another part. That's a big part. Again, I'm going to deal with it and do as much as maybe it's the minimum. The top minimum is what I call it.

The six fathers who had attended support groups reported mixed experiences. For some fathers their ability to attend or interest in attending was curbed by their level of functioning. For example, if they weren't feeling well enough to leave home they missed group. Two participants didn't feel they fit with the other group members noting how few men were in the group or how they were the only people in the group who were raising young children. Gordon's quote below illustrates his desire to be in a group of people who share not only his cancer experience but who also are inhabiting his the same stage of life – fathering young children.

Gordon: I mean most of the people are older. So it's like hard to relate to people who are in their sixties or seventies not that I can't relate but their kids are thirty or forty. My kid is young. I mean their kids are sitting next to them in the group and they're my age. ...So I guess it does help. I just wish there were more people to connect to in my age group. I looked around and there is plenty of stuff if you are in your 20's or 30's or if you are a kid, or if you're old but there doesn't seem to be anything out there for our age group.

Some fathers reported finding it helpful just to be in a room with others sharing the same experience. Two fathers described helping others as their primary motivation to attend a group. For example, offering ideas for alternative treatments or encouraging people to get second opinions.

Bob: So if I can help someone: A) not go there into that deep hole and stay there and I can help drag em out I will. And if I can help them stay the course or find alternatives to heal themselves, like working with ...whatever alternatives we can come upon. There's tons of resources out there that I probably don't even know about but there's ways that people can get beyond this cancer. Cancer doesn't need to necessarily mean it's a death sentence for everybody.

Tim who had initially declined attending a support group early in his cancer experience changed his mind about participating in groups when he felt better and had successfully completed treatment. Not feeling as vulnerable appeared to make being in the group easier and less threatening. Similar to other fathers, he reported the desire to help others as his motivation.

Tim: Now I enjoy going to the meetings more. ...I don't think it is arrogant of me. I don't mean to be arrogant, but I see myself more as somebody who is surviving and thriving and hopefully a little bit of an inspiration to other people who have uncertainties and don't know if they can endure this and don't know where this is going and they're looking at me in the chair and their saying, "hey, you know he made it." So I really do I enjoy going to the meetings now and maybe that's my excuse. I don't know maybe I'm telling myself that. Um cause I do to a point I enjoy hearing the discussion of what other people are going through.

While not unified in their opinion on the benefits of attending support groups for themselves the fathers welcomed them for their kids. Children of six of the fathers had participated in various activities in a local community organization that offers psychoeducational support for families experiencing parental cancer while raising young children. Some of the children had attended support groups and/ or a summer camp for kids who have a parent with cancer. Several of the men linked their own support to that of their children, saying that as a father seeing your children supported was more valuable to them. These fathers indicated they felt the groups for their children helped

reduce their children's sense of isolation, reduce their fears, and normalize an unusual life experience. These findings suggest the reduction of their children's distress alleviated some of the father's distress as well.

Eric: These organizations helped him quite a bit not only bond with other kids who are going through it with parents with cancer. Cause he's an only child in the house so he doesn't have anybody else to bounce this off of except his parents, adults you know. Once he knew that there were other kids going through the same thing, the fact that he was able to mingle with and socialize with other kids, they forget about the cancer and just do what kids do with that realization that I'm the same.

Charlie: You know the group helps tremendously cause, he got a chance to talk to other people whose parents are surviving and other people who aren't doing as well and other people who lost their parent and guess what they still come from the group, they are alive [he's talking about the children who have lost a parent], and they're doing well. It really taught me a lesson about how important these groups are to the little ones and getting to meet everyone. He really, really, I wouldn't say he enjoyed it, because how can he enjoy it, but at the same time he has gotten a lot out of it. He wants to go.

Mike: Well first of all me and my wife really do think that the kid's camp is a wonderful thing. The first year, I mean they have been going two years now. The first year they were pretty stressed out, the kids were and going to the camp they had forgotten everything for about three or four days about what was happening in the family. All they could talk about was camp for the next two weeks after that all they could talk about was camp. It really did get their minds off of the situation at home.

Discussions of support were woven throughout the interviews and the participants shared that books were another source of support. Three fathers indicated that they had read books that they found to be motivational and helped normalize their experience. For Mike, who reported great reluctance to attending a support group, the idea of turning to a book was appealing.

Mike: I'm not one to sit in support groups and listen to other guys talk about their problems. I'm sure a lot of other people are like that but like when I started

reading those motivational books, it was a lot easier for me. It was almost like sitting in a support group but I get to sit at home and read it by myself and have my own thoughts about it. You can shut it anytime. Support groups are not necessarily my thing but books are. I mean I never used to read anything. I used to read some books about like work or a magazine but I have come across a couple of motivational books and I really did thought that was a lot better help for me then actually sitting in a group.

Several fathers expressed a desire to read a book that was specifically geared toward fathers facing cancer. A book which focused primarily on practical needs rather than emotional support was indicated as being more attractive to these participants.

Mark: to me it almost would be like here's a check list of things that big areas of your life that cancer will impact you on whether it is potentially financial or dealing with the kids, how to handle health care, questions to ask, not specific about your diagnosis but just financially-based and general how to handle things probably from an inner side/emotional side. That's somewhat hard because people will cope differently but I guess that would have been something I would have be more apt to look at. I think you can reach emotional side by address some of those areas and kind of weave that in because if I would have known up front all of the things you need to get set up.

Eric: Yeah, Yeah, we're more technical in nature, right, right. Yeah, we're not dealing with the emotional stuff. We'd rather have that book. That book you know get things in order, leaving things to your wife or your son. Dealing with how to talk to your teenage daughter or your teenage son. You know from somebody who's been through it. I think that would be good. ... Yeah, kind of a guide. I wouldn't say a "How to" cause again, we're macho. We want to do it our way. You know a guide. "You don't have to do this..." [He laughs].

They recognized their difficulty getting too close to their emotions, yet they did acknowledge the value of emotional support and suggested this type of information would be better received if woven in under the guise of practical support.

Bob: I think men probably are more practical then the emotional side so you know some kind of a guide for a man though we probably don't read directions very much, in general, I don't. I try to put it together without looking and if I have to

look I look but... I think in general men probably want more practical advice versus the emotional side and of course the family and women of those people probably want them to have more emotional support. So you have to kind of work and sneak that in somehow ...a practical guide, here's how-to dad, stay the course.

Finding Meaning

The ability to search for understanding and find meaning in the face of adversity has been described as crucial for building resilience (Walsh, 2006). These findings reveal that all of the fathers in this study worked to make sense out of this experience and consequently were able to clothe it with meaning in a way that enabled them to forge resilience. Unlike other aspects of their experience fathering through advanced cancer, a diminished level of functioning didn't appear to preclude the participants from finding meaning in the face of great uncertainty and multiple losses. Nor did still being in the middle of the experience negate these fathers' ability to seek meaning.

Prioritize Family "Family comes first."

Learning to prioritize family over work in their lives was the predominate lesson learned. Multiple times fathers mentioned that living with this life-threatening disease taught them that "family comes first."

Mike: Your feelings towards people and situations in life change. It really does. You learn every day. About what's important and how to put things into perspective and what concerns you first. Family comes first. But you learn every day of things that are more important. It makes you stop and kind of realize what life is all about. Family, raising my kids, making sure my wife is happy. Yeah. It's all about family.

For those fathers who had been the primary breadwinner in the family this meant striving to achieve a better balance between family and work. Most of these fathers

described themselves prior to their diagnosis as hard workers. Independent of whether they were employed in blue-collar or white-collar jobs, they described working in a way that robbed them of time with their family. Bob, who is just completing treatment and hoping for a containment of the cancer, captures this sentiment in the quote below.

Bob: Oh right before cancer was work, work, work. I worked as much as I could. I would have put working and making money for my family [as the priority]. ... I've already planned not to burn myself out with work. That I'm going to limit myself on how much I'm going to work and when I do work and make family time. So those are the things now that I have this, I don't know, like gift of life to continue on that you know, those are things I want to do. ... I realize that your family needs to be first on your list instead of last sometimes. And that's important this next time around, would it happen again, that I would probably take more opportunity to really just have one on one time with my kids. Knowing that dying was coming on at first you know we just didn't really know. But as that time were to approach I think my next ideas would be to spend more quality time with them one on one and really just hang out. And maybe that... this next time if it were to occur I would be aware of... and say you know what? This is the last go. This time around we maybe are not going to get another chance.

This renewed focus on the family led to a deeper appreciation for their wife and children as a result of the diagnosis. Finding renewed meaning in their family relationships and their responsibilities as a husband and a father strengthened them and helped them better negotiate the barriers this disease experience placed in front of them.

Chris: We've always had a loving bond but it seems like, she helped me so much. I really appreciate it. Yeah, I guess we got closer or deeper. Things changed a little bit. Me and my son too, the fact that we are got some more time together so I think we got a closer relationship.

John: It helped me somehow to be, I received some correcting in the area of tolerance. So I was able to develop more spirit of tolerance and deeper love again for my kids. Cause when I first get this cancer issue the love I had for my children was burning, the love I had for my family was burning, I said I'm not leaving these kids, I'm not leaving my wife, so that love that was not all that hot was higher and hotter when I faced this sickness and when I came back [from the hospital] that love has not gone down.

Eric: Yeah, I mean your perspective changes; you appreciate your wife a lot more cause you find out what real love really is. M: In what way would you say? Eric: in the fact that she sacrificed to take care of me.

Those fathers who were raising teenagers described this deeper appreciation of family as contributing to their channels of communication being more open. As Scott describes:

Scott: I'm going to tell you it brought me and my grandson a lot closer. You know my grandson; he usually talks to my wife a lot about everything. But every now and then, she's back there and he comes up and comes out here and sits down and I have a conversation with him not about my sickness and I never done this and ...we sit down and ...we are talking about you know basketball or how he is hoping to get into college.

Fathering With Intent

“I try to be more conscious of what I’m doing with them.”

Each of the fathers noted a renewed sense of determination to be good fathers.

This cancer experience made them more thoughtful and intentional in their parenting.

Mike: I mean there are little things I have changed where I try to be more conscious of what I'm doing with them. Before I would try to go, go, go with them and maybe try to...you would pass over little things you want to teach them along the way and you just... I'm just too wound up to slow down and actually teach them and now you kind of slow down and kind of like, hey, I'm skipping over this and I need to take them time to teach them a little more than I had been in the past. Just work with them a little more which I think makes them better kids, makes them stop and think a little more.

Mark: The more we can focus on what are the kids thinking. What do they actually need here? Do they need us to sit down and cuddle with them and be in our lap and talk through this or do they need us to just tell them the basics and then have them go play with their friends and go on a sleepover or do whatever?

Scott: You know before this there would have been some stomping going on but I just looked at them and told them you guys gotta just do better. But now... it made me take a different path to how I was going to raise them. Cause before it was spare the rod, spoil the child. But...You know, I started talking to them.

...changing my parenting skills... you know more love and care and less [he makes a roaring sound]. ... like I said less roar sound and more love.

Living in the Present

“I think we’ve really tried to focus with the kids on living in the present.”

Learning how to parent through uncertainty was a very important lesson described by all of the fathers. A keener sense of their mortality led each of them to value each day and that shifted the focus of their fathering from an orientation toward the future to being oriented more in the present.

Mark: I think um ... it’s a good question. I think we've tried to live in the present to a certain extent. My personality is really probably forward looking I’m always looking to save for future things and kind of sacrifice for future that is kind of my personality. My wife is definitely the opposite. She’s more free flowing live in the present. I think over the years moved more towards that. So I think to answer your question. I think we've really tried to focus with the kids on living in the present.

Charlie: I think my lessons are, number one, Tell the truth. You know just be honest. Cause kids are more resilient than you give them credit for and they gotta know the score. The second thing is, find ways to compensate for your lack of energy and I don't know where you find it. I don't know if maybe you keep a diary and figure out what level... where you are the brightest even if you take your kid out of school a couple of times a month to touch that area where you are the brightest. Do it. Do it. Because schools get it. I mean they understand what you are fight for. And the third is, I'd say the kids need to get into some kind of group counseling or mediation. Personally I think it has been greatly helpful for Anthony. ... That's what I'd say, those three things.

Each of these fathers worked to be hopeful and focus on the positive.

Bob: It just brings it more to awareness that hey my time really is limited potentially here on this planet and how do I make the best of it. So what does that mean for now? It means ...make the best of everyday we can. That's the biggest realization. Even though some of those days have been extremely challenging, in my mindset anyways, still try to make our day good. Let's leave it on a positive note. Let’s not dive into the negative and go down that train of dismal situation and realize it is what it is.

Tim: But we really don't have a sense of doom. We have more of a sense of let’s have some fun today and fun next week. And again you have probably heard it

before and it's kind of perverse but we live life a little more vibrantly than we did before myself and my family.

It can be a struggle to stay focused on the present and be appreciative of each day in the midst of a life-threatening disease. This effort was not indicative of the denial of a dire situation. None of these fathers described this task as easy. They all shared times where they slipped into despair and struggled to find and focus on the positive. Yet what Gordon's quote below captures is that they realized the value of enjoying the moment and tried.

Gordon: We are here now let's not focus on that or we'll lose the little bit of time we have left. Yeah, we don't know how much that is but. It's hard. It's hard not to focus on what's screwed up or how screwed up it will be down the road. Hey, let's get the Christmas tree up and sit and watch it and enjoy it. That's really all for me. Be here today. Try to enjoy the moment. You know the reality of... I don't know how many moments there are going to be so let's enjoy it. It's not like I'm consciously thinking that every moment. But I just sort of live in that, okay well let's just live in that now.

Still Searching

“Maybe it is something that maybe is ultimately beneficial to them for their life.”

While they learned a lot, the fathers recognized that there were still unknowns. They were still living with cancer. This is exemplified most profoundly in their concerns for their children. What will this experience mean in the long run for their children? They expressed hope that ultimately their children will grow from this experience. Mark's quote below captures this sentiment.

Mark: At least the two older ones I think they definitely understand that concept that some things are just out of your control so... it's hard for me. ...maybe ultimately, to look at a silver lining, the things they may get out of it, I'm going through chemo or I'm in the hospital going through surgery and my 13-year-olds got to do her homework, the big thing is math homework, my wife is somewhat illiterate at math and I have a mechanical engineering degree so that's my

territory, I used to really spend hours and hours with her going through this and lately the last couple of years she hasn't need my help a whole lot she's gotten a lot better at it and I think it's potentially because I don't help her as much and you know and work through the answers with her and I think she thinks "dad's not around I have to figure this out myself" so there's some silver lining to some of this.

CHAPTER SIX

Discussion

This study is notable in its examination of the parental cancer experience from the perspective of fathers living with a diagnosis of advanced cancer while parenting young children. Though the literature examining the experience of parents diagnosed with cancer while raising young children has grown over the last two decades, little attention has been paid to parents living with *advanced* cancer. Moreover the voice of fathers from this body of work is nearly absent. This study attempted to fill an additional void in the literature by including participants who are currently living in the United States and thus sheds some light on this country's social and institutional policies that may impact a father's level of resilience. The process of resilience in fathers facing advanced cancer while parenting young children was constructed through qualitative data analysis. This model identifies the contextual and intervening variables that are a part of fathering through advanced cancer and provides a framework for understanding the ongoing and dynamic process of resilience experienced by these participants.

The primary research questions guiding this investigation were (a) How do fathers living with an advanced cancer diagnosis navigate their role as a father of young children, (b) How do they perceive this experience impacting their individual as well as their family's functioning and (c) How do they interpret the meaning of this experience. From this study's analysis we learned that when these fathers were diagnosed with advanced cancer their roles changed and the financial pressures mounted. Concerns for their children permeated their cancer experience and influenced their treatment decisions as

well as their motivation to survive. Change, uncertainty and loss were woven throughout their experiences as these fathers teeter-tottered between hope and despair striving to live and parent in that place of hope. Given the continuous yet unpredictable nature of their disease experience, the experience of these fathers illustrates a nuanced conceptualization of the resilience process as an ongoing and at times hard fought struggle to counterbalance the barriers with their various protective strategies in order to parent and live well in the midst of uncertainty.

Barriers

Though resilience is the main finding of this study, understanding the enormous hardships identified by these fathers provides a critical context within which resilience was forged. Thus, the challenges described by the participants as part of their experiences fathering through advanced cancer will be discussed in this section. While the findings suggest there are numerous barriers throughout the cancer experience of these participants, three themes were particularly salient in terms of their resilience process, their level of impairment, uncertainty for the future and the degree of financial burden. These barriers weighed heavily in the lives of these fathers challenging their ability to parent from a place of hope. Each of these barriers has been supported in previous research. Similarities and differences between this study's findings and the current cancer literature will be discussed.

Level of impairment. Level of impairment describes the symptoms experienced by the participants as a result of their cancer or its treatment and the degree to which those symptoms impaired their ability to function and perform each of their father roles.

All of the participants described episodes of intense discomfort caused by the presence of the cancer and/or the accompanying treatments that are supported in the broader cancer literature as well as in studies specifically examining parental cancer. The most common ailments described were pain, fatigue and nausea. The prevalence of these particular symptoms is corroborated in the literature on advanced cancer with pain estimated to be experienced by greater than 75% of those patients (Teunissen, et al., 2007; Walsh, Donnelly, & Rybicki, 2000). Fatigue and nausea were somewhat less debilitating and all of the participants reported being able to eventually find strategies to manage primarily through medical interventions but pain symptoms remained more elusive.

Studies show that unmitigated pain can impair physical as well as psychosocial functioning in patients with advanced cancer (Mori, Elaysem, Reddy, Bruera, & Fadul, 2012). Consistent with the literature, several fathers described experiencing pain that was so intractable it left them unable to perform the most basic physical (e.g. walking, dressing, eating) and psychosocial (e.g. communicating with family) life tasks. These episodes could last hours or days and at times made fulfilling their fathering roles nearly impossible.

These episodes of unmanageable pain led to the loss of various father roles. The loss of primary parenting roles is supported in parental cancer research examining the experience of mothers and fathers (Elmberger, Bolund, & Lutzen, 2002, 2005; Fitch, Bunston, Elliot (1999); Ohlen & Holm, 2006) and Walsh, Manuel, & Avis, 2005). While many roles these fathers described were disrupted or lost, as in Elmberger, Bolund & Lutzen's (2002) study of Swedish fathers, particularly salient to these participants was

the disruption in their father role as a provider. As the findings described, the loss of their ability to fulfill their perceived role due to their incapacitation had a cascading effect on the entire family and when coupled with the all the uncertainty embedded in the cancer experience, challenged their resilience.

Uncertainty. Uncertainty is among the most commonly reported experiences described by patients living with cancer across cancer types, socio-economic status, and ethnicities (Shaha, Cox, Talman, and Kelly, 2008). A diagnosis of cancer has been found to cause enormous uncertainty and distress in all domains of the patient's life increasing with a poorer prognosis (Germino et al., 1998; Zabora et al., 2001). Uncertainty in illness has been defined as the incapacity to accurately predict outcome, attribute meaning or assign definitive values to events and/or objects related to the illness experience (Michel & Braden, 1988). Though fluctuating across the disease trajectory, uncertainty about what lay ahead undergirds the entire experience of living with advanced cancer beginning even prior to the specific diagnosis (Rolland, 1994, 2005). The unpredictability of the experience can increase a person's vulnerability to distress or negative outcomes and act as a barrier to resilience (Haisfield-Wolfe et al., 2012). Consistent with the literature, the fathers reported numerous disease-related uncertainties linking primarily to which treatment paths to follow, their ability to tolerate the treatments, the ultimate effectiveness of their treatments and the chances of their survival. One source of this uncertainty has been described in the literature as due to a limited or complete lack of access to information (Shaha, Cox, Talmand, & Kelly, 2008). While there was a great deal of confusion immediately following their diagnosis, it is important to note that this

uncertainty extended beyond the initial confusion and was not related to possessing insufficient information but inherent in their diagnoses. In the case of each of these participants it was simply not possible to completely predict the rate and trajectory of the disease, their body's ability to tolerate various treatments or the outcome. These disease-related uncertainties have been described as the most difficult aspects to accept for both the patient and their family (Rolland, 1994).

This disease-related uncertainty rippled into all domains of their life and played a crucial part in shaping their fathering experience as found in previous studies. For example, this uncertainty colored decisions they made as fathers about how to explain the unknown aspects of the disease experience to their children, about how to plan daily life activities as well as the ability to make future plans as a the family. These challenges are supported in the parental cancer literature. For example, in their examination of communication patterns between parents living with advanced cancer and their young children, Kennedy & Lloyd-Williams (2009) found the parent's own uncertainty about what to expect acted as a barrier in their ability to communicate with their children. These interactions have been found to be further complicated by the age of the children with the parents expressing concern that younger children would not be able to understand (Barnes et al., 2002; Kennedy & Lloyd-Williams, 2009). I found that fathers with children younger than 7 years of age shared this concern.

Other studies of parental cancer found the ambiguity post-treatment influenced family plans for the future making it difficult for some families to organize while propelling others to take advantage of the time they had (Elmberger, Bolund, & Lutzen,

2000; Semple & McCance, 2010). An experience shared by the fathers in this study. For example when Bob shared his desire to take a family trip yet was unable to move forward with the plans until they had a better understanding of how his treatments were progressing. He eloquently described this process as “living in mystery.” Moreover, for some fathers in this study the uncertainty in looking to the future meant they found it necessary to try to prepare their children for navigating life without a father. A similar finding was reported in a study of mothers with breast cancer (Elmberger, Bolund & Lutzen, 2000).

Uncertainty regarding their ability to resume their provider role and return to work was an important theme in this study. Returning to work after a diagnosis of advanced cancer is very difficult and only the two fathers who were able to maintain their employment since their diagnosis were working at the time of these interviews. Consistent with the literature on cancer survivorship, their ability to return or resume work after disease-related absences were connected to both work and disease factors. People who have been diagnosed with cancer and employed in more blue-collar jobs are less likely to return to work (Bradley et al., 2005). The findings from this study were mixed in this regard. The fathers in this study who had previously been employed in positions that would be described as blue-collar and required a great deal of physical labor had not yet returned to work while the two fathers who had been able to maintain their positions were working in jobs that would be characterized as white-collar. However, this study demonstrates that job loss can extend beyond those employed in blue-collar jobs. Fathers employed in such white-collar position such as sales and health

care also connected their inability to return to work due to their impaired physical and cognitive functioning.

The severity of the diagnosis has also been shown to influence cancer survivors return to work. Studies in the United States as well as internationally have found patients with advanced disease or diagnoses that are linked to a shortened length of survival, as was the sample of fathers in this study, are significantly more likely to be unemployed (Choi et al., 2007; Yabroff et al., 2004). Though all of the participants in this study who were working outside the home prior to their diagnosis expressed a hope to either continue in their work or eventually return to work, their inability to maintain employment throughout their cancer experience placed a financial burden on all of the fathers. As the findings reveal, for some the financial consequences were quite severe and jeopardized their resilience.

Financial burden. The uncertainty combined with a diminished level of functioning shaped the financial health of the participants. The examination of the financial burden of cancer is a relatively new area of exploration in the cancer survivorship literature yet it is recognized that a cancer diagnosis brings significant financial hardship to families (Meropol et al., 2009). The cost of cancer treatments has been associated with the depletion of savings and bankruptcy as well as having implications for treatment including delays in treatment and reductions in compliance (Meropol et al., 2009; ACS study).

An exploration of the financial burden of cancer has been largely absent from the parental cancer literature yet it was a prominent theme in this study acting as a substantial

barrier in the resilience processes of these fathers. With two exceptions, the participants in this study reported experiencing financial hardship as a consequence of their diagnosis limiting or eliminating their ability to work. One of the fathers who did not report experiencing financial strain had been a stay-at-home dad prior to his diagnosis and his wife was the sole source of income in the family. Another father who has been able to maintain employment despite brief absences from work and thus not experienced significant financial burdens thus far, described having experienced multiple recurrences that required time away from work for treatment. He attributed his current economic security to workplace flexibility that allowed him time off as needed as well as an absence of a life-time cap in his insurance policy. Moving in and out of treatment over the last six years, the associated medical costs had been extraordinary and would have ruined him financially if he wasn't able to continue working and maintain his insurance.

Most of the fathers in this study were living exclusively on social security disability benefits which meant having to alter their lifestyles. Many fathers reported that this public benefit, while deeply appreciated, simply wasn't enough as the out-of-pocket costs mounted. For some the change was dramatic and included losing their home to foreclosure or selling their homes at a loss in a downturned market in order to move into smaller living quarters. For others it meant having to make decisions about the allocation of their resources sometimes having to juggle various household expenses such as whether to buy food or make a mortgage payment. For several fathers it meant exhausting their family's savings and for one participant it meant filing for bankruptcy. These financial consequences are just recently being reported in the literature. A recent

study found more than 60% of all bankruptcies in 2007 were medically related and three-quarters of those filing for bankruptcy had insurance (Himmelstein, Thorne & Woolhandler, 2009). A national survey of households effected by cancer conducted by the Kaiser Family Foundation (KFF) found 25% of insurance participants reported using all or nearly all of their saving to cover expenses (KFF, 2006). Several fathers in this study described exhausting all their savings and still not being able to meet all of the out-of-pocket expenses associated with their diagnosis and treatment. A number of fathers in this study reported relying on small grants from non-profit organizations and money from family and friends in order to cobble together enough funds to meet some of their basic living expenses.

At the time of the interview all of the participants reported having insurance coverage. However, for those fathers whose insurance was employer-based, the very real concern that they may be eventually fired caused them extreme distress. Studies have shown that cancer patients' who experience disease-related absences are at risk of not only losing their job but the employer-sponsored insurance (ACS Survey, 2009; Kim, 2007). Covering the cost of treatments for advanced cancer without the help of insurance can be catastrophic for families.

These financial concerns were particularly salient to these participants given their perceived father role of provider. They described a sense of duty to provide for the financial needs of their children and not being able to do so caused them considerable stress. In addition, this belief that it is their duty to provide for their children coupled with the high out-of-pocket costs shaped several fathers treatment decisions. This was

exemplified by Eric's consideration of foregoing future treatments should he experience a recurrence out of fear of leaving his family in financial ruin.

A diminished level of functioning, uncertainty about what lay ahead for themselves and their family and the tremendous financial strains that accompany a cancer diagnosis were considerable challenges these fathers faced as they navigated their cancer experience. Ultimately finding strategies that supported their adaptation to these barriers shaped these fathers' resilience and allowed them to tip the balance in favor of hope.

Protective Factors

Though the examination of the process of resilience in cancer survivors is growing few parental cancer studies have focused specifically on this concept. Moreover, no study to date has described the resilience processes specifically of father's living with advanced cancer. In comparing this study's results to previous studies in the parental cancer literature and the broader cancer survivor literature, several themes were supported. All the participants in this study demonstrated evidence of resilience or the ability to live and parent from a place of hope despite enormous uncertainty. This resilience was evident at various times across their experience fathering young children via multiple and sometimes unexpected pathways. Although these fathers reported some severe challenges as addressed above, the findings also indicated a number of strategies they utilized that supported their resilience including, role flexibility, open communication patterns, appraisal-focused skills, the positive evolution of help seeking behaviors, and the ability to find meaning in the experience. The findings suggest these

strategies served to counterbalance the enormous weight of the barriers altering the effects of the disease thus shaping the resilience process of the fathers toward a hopeful stance in their parenting.

Role flexibility. The fathers in this study described four primary father roles: provider, teacher, playmate and disciplinarian. The effects of the disease as well as the demands of treatment and the resulting side effects disrupted each of these roles as they were defined pre-diagnosis. Parental role change post-diagnosis is a common theme in the parental cancer literature (Elmberger, Bolund, & Lutzen, 2002, 2005; Fitch, Bunston, & Elliot, 1999; Hymovich, 1993; Semple & McCance, 2010).

Role flexibility has been described as a sign of resilience in the family resilience literature. For example, Walsh (2006) describes the ability of a family to be flexible in response to adverse events as a key process of resilience. Being diagnosed with advanced cancer meant these fathers' ability to function in their pre-diagnosis roles was impaired. This loss of role function is a risk factor potentially impeding these fathers' ability to move forward. The findings reveal these participants were eventually able to adjust their perceived father roles and reported their families supported what Walsh (2006) describes as a reallocation of roles.

The findings suggest these fathers found a way to adapt to this disruption by being flexible in their roles. For example, the effects of the disease and accompanying treatments led to substantial work loss for most of the fathers, disrupting their ability to maintain their primary father role of provider. As their level of functioning allowed, these fathers demonstrated a willingness to shift to a primarily domestic role though they

expressed some ambiguity about this transition. This was also found in a study of Swedish fathers (Elmberger, Bolund, & Lutzen, 2002). A finding also shared with the Swedish participants was descriptions of a positive aspect to this role change for example, the ability to spend more time with their children. Time they hadn't had when they were working outside the home. This was a critical gain for these fathers and one described in the literature as especially important to parent's diagnosed with advanced cancer (Sheehan & Draucker, 2011).

These fathers also demonstrated flexibility in their other father roles. For example, adjusting the physicality of their play or as Scott described tempering his discipline, "less roar, more love." The fathers demonstrated flexibility in the way they conceived their roles as well. For example, the teacher role, characterized by fathers as imparting critical life lessons to their children such as, moral values and the importance of being responsible. This role took on deeper significance and several fathers reported shifting their approach and being more thoughtful about taking or creating opportunities to teach these lessons in order to better prepare their children for a potential future without them.

It is possible the father's ability to adjust their roles, especially their role as provider, was supported by their hope that the change was temporary. For example, many of the fathers reported the desire to return to work at some level if their disease could be contained or managed. Another likely contributor was familial support. Each of the fathers reported that their spouses encouraged their taking the time they needed away from work in order to heal. Finally, it is possible that the changing role of fathers in

American culture both eased the transition from provider to domestic as well as fueled some of the ambiguity. A recent Pew Research survey provides context for these findings (Parker & Wang, 2013). The Pew survey of 2,511 adults across the country in November of 2012 was combined with interview data from the U.S. census that was sponsored by the U.S. Bureau of Labor Statistics and collected from more than 100,000 participants from 2003-2011. The results of this study suggest that the time fathers are spending engaged in domestic work and child care has increased dramatically over the last several decades while the number of mothers who are employed outside the home has grown. Despite these changes, 75% of these men stated the ideal situation for fathers of young children is to work full time and 66% of mothers agree. While only 12% of adults surveyed stated it's best for mothers of young children to work full time. These results reveal the evolution of the role of fathers in the family as well as reflect the current climate of ambiguity regarding that role among the participants' larger peer group in this country.

Open communication patterns. As the findings revealed communicating with their children about various aspects of the disease experience was an ongoing process that began right at the point of diagnosis. With the exception of one father with very young children, they all used the word “cancer” when describing their disease. This finding differs from the study of Swedish fathers who were reported to rarely use the word “cancer” when speaking with children (Elmberger, Bolund & Lutzen, 2002). The disease-related uncertainty coupled with the uncertainty of how this might impact the children made knowing what to say difficult. Overwhelmingly, the fathers in this study choose to

give their children the “real scoop.” This was especially true for fathers of adolescent children. The challenge became how to give their children the real scoop while maintaining hope in order to avoid frightening the children.

This challenge to balance honesty with protection in communication with children has been reported in other studies as well (Barnes et al., 2000; Billhut & Segesten, 2003; Elmberger, Bolund & Lutzen, 2005; Fitch, Bunston, & Elliot, 1999; Shands, Lewis, & Zahlis, 2000). The fathers tried to buffer the realities of their prognosis with hope. For example, stating that while the disease couldn't be cured, they hoped the treatments would keep it under control for an extended period of time. A similar communication strategy was reported in a study of Swedish mothers diagnosed with breast cancer (Billhut & Segesten, 2003).

Consensus is growing in the parental cancer literature identifying communication as a critical factor in the children's and the family's adaptation to the disease experience (Edwards and Clark, 2004; Kroll, Barnes, Jones, & Stein 1998). Open, honest communication has been identified as essential to family resilience (McCubbin & McCubbin 1988; Walsh, 2006). Yet studies both in the US and Europe suggest there is a need for the availability of supportive resources to guide parents in their communication efforts (Barnes et al., 2000; Kennedy & Lloyd-Williams, 2009; Shands, Lewis, & Zahlis, 2000). Interestingly, in this study, while all the fathers reported finding it difficult to talk to their children, only one father reported feeling he didn't have the information to do so. This finding could be due to the engagement of several of the fathers in a community-

based psycho-educational support program for families living with parental cancer, thus having access to this information.

Appraisal-focused skills. While the fathers identified various strategies used to manage the challenges of living with parental cancer, the following three appraisal-focused strategies were most prevalent: self-talk, compartmentalization, and humor. Appraisal-focused strategies have been described in the stress and coping literature as modifying the way we think about or perceive a stressor (Folkman & Lazarus, 1988). Context matters here – the strategy must fit the problem. Appraisal-focused strategies have been found to be adaptive and promote resilience when there is no straight-forward solution or remedy to the stressor (Folkman & Lazarus, 1988). Such is the case with an advanced cancer diagnosis.

Constructive self-talk. Constructive self-talk has been described as an internal dialogue used by individuals to manage negative thoughts which can result in feelings of anxiety or depression (Hardy, 2006). Self-talk that involves a reappraisal of the stressor that is not based in reality and more closely resembles an act of self-deception can be maladaptive (Walsh, 2006). For example, denying the existence of the disease in a way that prevents the individual from pursuing treatment. These findings suggest the participants did not engage in self-deception. Each father reported a clear understanding of the seriousness of his disease. Yet they would use this skill to challenge negative thoughts with messages Walsh (2006) describes as “positive illusions.” This term describes a cognitive process that holds a selective positive bias despite an awareness of the level of threat and its implications.

The participants described using this strategy often when they were alone, often in the middle of the night. Living with cancer can be very isolating and these men reported many times when they were alone and struggling with intrusive negative thoughts or what John referenced as, “death messages.” It was in these moments participants described using constructive self-talk as way to shift their cognition away from negative to more hopeful thoughts or positive illusions. This strategy has recently been examined in the breast cancer survivor literature with mixed results. For example one study found constructive self-talk to be effective in managing distress specifically experienced during the time between diagnosis and surgery (Drageset, Lindstrøm & Underlid, 2010). Participants in another study examining the effectiveness of a positive self-talk intervention reported no significant change in levels of distress (Hamilton, Miedema, MacIntyre & Easley, 2011). Yet, the fathers in this study found positive self-talk to be effective in helping them refocus on what they could control – their response.

Compartmentalization. Another strategy participants described using to manage intrusive thoughts was to compartmentalize those concerns. The fathers reported this strategy as being particularly effective in managing their worries in those periods between treatments and medical appointments. These waiting periods can be extremely stressful for individuals with cancer and their families. The fathers were not denying the seriousness of the situation or the weight of their fears but recognized that there was nothing they could do to affect the outcome. This strategy has been described as form of *distancing* in the stress and coping literature (Folkman & Lazarus, 1988).

Compartmentalizing worries has been associated with low levels of psychological distress in persons diagnosed with advanced cancer (Zabalegui, 1999).

Humor. The ability to find humor in the midst of the cancer experience can have a protective effect that can promote resilience (Walsh, 2006). Humor has also been described in the stress and coping literature as another form of distancing that can be adaptive in the face of stressors (Folkman & Lazarus, 1988). In each interview the participants shared a variety of humorous experiences since their diagnosis and several of the fathers identified humor as an important strategy for managing their fear, pain, and the anxiety of the unknown. For some fathers this humor had an interpersonal effect drawing their family into a shared “inside” joke about the disease or its effects which they perceived as having a positive effect on their family. Humor among people living with cancer has been correlated with decreased levels of anxiety and discomfort as well as increased immune functioning (Moore, 2005). Moreover the use of humor has been found to be especially beneficial to men diagnosed with cancer. A recent ethnographic study of 54 men diagnosed with prostate cancer and participating in a support group indicated that humor played an important role in promoting inclusiveness and easing men into discussions about sensitive topics such as death or sexuality (Oliffe et al., 2009).

It is critical to acknowledge that an over-reliance on strategies such as self-talk, compartmentalization, and humor as a defense against thoughts or feelings of vulnerability in a manner that denies the existence of these feelings can be detrimental to the resilience process. Additionally, if misused, these techniques can have negative relational consequences by blocking communication pathways at a time when open,

honest communication can be especially important (Folkman & Lazarus, 1988; Walsh, 2006). This study did not include interviews with the spouses of these fathers thus cannot conclude if these strategies were experienced by family members in a negative way. Given the widespread use among these participants, it warrants further examination in future studies.

Accessing support. Access to and utilization of supportive resources has been found to be crucial factors in shaping resilience (Walsh, 2006). These supportive resources can take various shapes including emotional and functional and be received from both formal and informal sources. Similar to a report of Norwegian fathers participating in a parental cancer study, the fathers in the present study were reluctant to reveal their need for psychosocial support (Helseth & Ulfsaet, 2005). It is widely accepted in the literature that men have difficulty acknowledging the need for support as well as difficulty asking for help in the face of emotional distress (Ridge, Emslie, & White, 2011). These findings aligned with the literature to a point. While they reported no difficulty seeking medical attention for their physical experiences of the cancer and its treatments, the majority of the participants described having difficulty asking for any other type of support in the initial stages of their cancer experience. The findings indicated an evolution in the help-seeking behaviors of the fathers in the present study growing more open to seeking and receiving support as they moved along the disease continuum.

This initial reluctance to admit or seek support appeared at least in some part tied to their perception of the social construction of gender roles and the concept of a

hegemonic masculinity that equates being a man with being strong, successful, independent and capable of supporting their families and taking care of their problems on their own whereas, the inability to do so was perceived as being weak (Connell & Messerschmidt, 2005; O'Neil, 2008).

This conception of manhood as being the lone hunter who doesn't expose vulnerability is a potential barrier to resilience in the context of a cancer diagnosis and may explicate some men's help-seeking behavior in the facing of a cancer diagnosis (Nicholas, 2000). This concept has been explored in the literature primarily examining the experiences of men diagnosed with testicular and prostate cancer. In a pair of papers using data obtained from a longitudinal study examining the experiences of men diagnosed with prostate cancer, Gray et al. (2000a,b) reported that the participants' traditional views of masculinity thwarted their attempts at expressing emotional vulnerability and negatively influenced their help-seeking behavior. One study specifically noted that the majority of the participants were reluctant to share their cancer experience and relied on their spouses as their primary source of emotional support (Gray et al., 2000b). This finding was shared by each of the fathers in this study though for several fathers their wives were not their only source of emotional support. Overtime several participants reported becoming more comfortable with accepting various forms of support including emotional support with their wives often acting as the gateway to that support. This finding is collaborated in a study of men's help-seeking behaviors that specifically examined who influenced the decision to seek emotional help (Cusack, Deane, Wilson & Ciarrochi, 2004). The Cusack et al. (2004) study found intimate

partners and health care professionals had the strongest influence on the participants' decision to seek help.

In some cases the wives tempered their husband's reluctance by providing a reframing of traditional views of masculinity creating a context in which it was normal and acceptable to be vulnerable in the face of this life-threatening disease. Other participants reported their wives sought psychosocial support for the children. This type of support was embraced by these fathers and several reported participating in family support programs. This finding aligns with literature that has demonstrated that men are more likely to seek help if they perceive it as a means to help others (O'Brien, Hunt, & Hart, 2005). The desire to help others also influenced the decision for some of the participants to attend disease-specific support groups. For example, one father reported an unwillingness to consider attending a disease-specific support group while he was feeling both physically and emotionally vulnerable as result of the cancer diagnosis and its treatments. However once he had successfully completed treatment and was living with no evidence of disease, he attended the support group and reported his motivation for doing so was to be an inspiration for others. Another father characterized his motivation for attending a disease-specific support group in addition to receiving support as primarily to provide information and inspiration to others about the importance of getting second opinions and sharing his experience with complementary and alternative medical approaches to healing.

While several fathers described themselves as not "group people" and characterized their desire to "do this on their own" as contributing to their reluctance to

attending cancer support groups, only two fathers reported not attending any type of formal support group and one of those fathers indicated a willingness to go yet did not have the means to attend as he did not have access to a vehicle. This finding contrasts with the study of Swedish fathers who described informal support from family and friends as adequate and thus psychosocial support from outside this circle was not needed (Elmberger, Bolund & Lutzen, 2002).

The fathers in this study eventually accepted the need for some type of psychosocial support. Several fathers indicated a preference for practical support delivered in the form of written material designed specifically for their population. For some fathers, this support was related to their role as providers in the family. For example, one father mentioned wanting guidance about how to manage some of his investments. Several fathers indicated they would like to better understand how this experience impacts their relationship with their spouses and how to navigate those relational challenges. Other fathers noted a desire for information about how to support their children through this experience, specifically how to address their children's questions and concerns about death. Several of the fathers indicated that if this information was contained in a single resource, they could refer to it as needed rather than on a schedule predetermined by a group.

The participants in this study described an evolution in their ability to seek and accept help both from family and friends as well as from the community that extended beyond emotional support to accepting financial support. It is likely that the intensity of the physical impairments contributed to the evolution of the help-seeking behavior of the

fathers in this study. In addition to the influence of their spouses on their help seeking behavior, the fathers reported the harsh realities of living with cancer and accompanying treatments made denying the need for help virtually impossible to them, especially when they were too impaired to fulfill their role as provider. The majority of the participants reported receiving financial support from family, friends or from local community organizations in addition to public support primarily in the form of Social Security Disability Insurance. Economic security has been found to positively influence family resilience (Walsh, 2006) and this financial support played a critical role in the resilience of these fathers.

The examination of the impact of the financial strains associated with an advanced cancer diagnosis on individual and/or family resilience is nearly void in the cancer literature despite the wide acknowledgement that these burdens can be extreme. Financial challenges have been noted to a degree in the parental cancer literature. For example in a study contrasting the experience of American single mothers diagnosed with breast cancer with married or partnered mothers found the single mothers reported more financial and work-related worries (Lewis et al., 1996). Interestingly, the fathers in the Swedish study discuss finances in terms of something they needed to have control over suggesting some level of financial security (Elmberger, Bolund & Lutzen, 2002). This lack of attention in the literature to the psychosocial impact of cancer-related financial burdens could be reflective of the newness of this area of study. It could also be reflective of the origins of most of the parental cancer literature coming from European countries particularly Scandinavian countries. These nations have family and work policies that

differ from the United States and may provide buffers against financial hardship in the face of disease. These findings provide a critical window into the extreme burden these financial strains place on fathers responsible for raising children while facing their own cancer diagnosis.

Finding Meaning

Finding meaning in the midst of debilitating pain, enormous uncertainty and dwindling financial resources would seem an extraordinary accomplishment. Yet the fathers in this study would not characterize their ability to make meaning from this experience as particularly courageous or extraordinary but rather as a necessary path to a reasonable quality of life. This search for meaning has been noted by existential scholars to be a primary human motivation reflecting a deep desire to make sense of life (Frankl, 1997).

Finding meaning in the face of adversity such as a diagnosis of advanced cancer has been found to be a critical component in the resilience process (Walsh, 2006; Patterson, 2002; Richardson, 2002, Rutter, 2012). The present study suggests the value of meaning in the midst of living with advanced cancer to the fathers' resilience process. The term *meaning* can be illusive and has been broadly characterized in the literature under two larger categories, global meaning and situational meaning (Park, 2010). A recent comprehensive review of instruments for assessing meaning synthesized the descriptions of meaning in the literature to arrive at the following definition of meaning as a highly individual perception, understanding, or belief about one's own life and

activities (Brandstatter, Baumann, Borasio & Fegg, 2012). This definition of meaning aligns closely with the experiences of the fathers in the present study.

The participants in this study were in the midst of the disease, some with clear evidence of cancer in their bodies, others in a phase of watchful waiting. Each father realized the serious threat this diagnosis posed yet, they described finding various meanings in their experience. The findings suggest it was this understanding of the severity of their circumstances that guided them toward a changing perspective of their role as a father that encompassed the lessons they have learned thus far. Most of the fathers described a realigning of their priorities as a result of their cancer experienced to date. Many reported privileging time and efforts at work over time and efforts with family prior to their diagnosis. Placing work as a priority in life was related to their perceived father role as provider and combined with the financial realities necessitating work and for several participants, societal expectations. The fathers reported a shift in priorities to use their words, “put family first.” This reshaping of priorities corroborated findings in the parental cancer literature (Helseth & Ulfsaet, 2005; Semple & McCance, 2010). Moreover the participants indicated a desire to father with more intent and not simply move through interactions with their children without thought noting their belief that these interactions could enhance their children’s development. This renewed sense of purpose in fathering shaped the meaning they attributed to their role and these findings suggest this had a protective effect supporting their resilience in the face of their disease.

A renewed sense of meaning in life has been associated with lower levels of distress in individuals diagnosed with advanced cancer (Breitbart et al., 2010). Breitbart

et al. analyzed the impact of a Meaning-Centered group intervention for people diagnosed with advanced cancer. They randomly assigned 90 men and women living with advanced cancer into the Mean-Centered group or a more traditional supportive therapy group. The findings revealed participants engaged in the Meaning-Centered intervention group experienced a significantly improved sense of meaning and reduced levels of anxiety in comparison to the participants in the traditional supportive therapy group.

In addition to finding deeper meaning in their fathering role, several participants described shifting their orientation from one that was primarily future-focused to one that was more focused on the present. This change in temporal orientation from future to present has been attributed to supporting resilience (Rolland, 1996; Walsh, 2006). As did the fathers' reports of living in a state of what one father described as "guarded optimism." This phrase acknowledges the seriousness of the disease and reflects a conscious decision to live with an orientation toward hope. Searching for the positive in a cancer experience has been reported in the parental cancer literature (Billhut & Segesten, 2003). In the case of most of these fathers their hope was to live as long as possible while making the most out of the time they had with their children. A similar finding was reported in a study examining interactions between parents in the terminal phases of advanced cancer with their adolescent children (Sheehan & Draucker, 2010).

A caution about interpreting the phrase "guarded optimism" and other references participants made about the value of focusing on the "positive." It is not uncommon in current popular culture to equate a positive attitude with better psychosocial functioning

in those living with cancer and at times there have been implied connections to improved disease status. While a positive affect has been associated with lower pain levels (Zautra, Johnson, & Davis, 2005), overall the empirical literature does not support most of these claims equating a positive attitude to a positive psychological or physical outcome (Coyne & Tennen, 2010). Moreover, this perspective can trivialize the monumental challenge of living each day with a life-threatening disease such as advanced cancer and places an inordinate burden on people to navigate the experience with a smile on their face less they contribute to the progress of the disease (Moynihan, 2002). These findings suggest the participants made a conscious choice toward optimism and hope with full knowledge of their dire circumstances. The participants' ability to do so fluctuated throughout the cancer experience and setbacks with their treatments or severe impairment made this very difficult. The fathers in this study reported they found the decision to focus on what was good in their life made the days brighter not only for them but for their families as well and helped tip the balance toward hope.

Limitations

The findings of this exploratory study are intended to offer a rich description of the experience of fathers living with advanced cancer while parenting young children which may be beneficial to researchers, policy-makers, families facing cancer and the practitioners who work with them. It is important to note several limitations with this study prior to discussing the implications. While this sample was diverse in its inclusion of fathers representing a wide range of socioeconomic backgrounds, it was not as culturally diverse as hoped for initially. Additionally the sample size was relatively small.

As a result, some themes were not able to be examined more fully such as factors in the family history of the participants that may have shaped their resilience process.

The cross-sectional nature of the design is also a limitation. The decision to use this design was made in large part out of not wanting to tax fathers in these circumstances where time and energy are precious. Yet, for all of these fathers, their cancer experience was continuing to unfold. Being able to examine if the shape of their resilience shifted over time or was challenged at particular points in time, as the Family Systems Illness model suggests, could have enriched these findings.

Selection bias may serve as a limitation in this study. All the participants volunteered to be part of the study which may have led to these fathers possessing certain characteristics which caused them to join the study. As a result there may be differences between these fathers and those who chose not to respond to invitations to participate. It is possible these fathers were more willing to be open about their experiences than fathers not in the study. There were no single fathers in the study. It is possible that the fathers who agreed to participate did so because they had a spouse at home to care for the children while they were being interviewed.

Finally, the inclusion of the whole family would have added to these findings. The addition of spouses and children could have enhanced the study by adding their perspectives on how they felt the diagnosis impacted the participant as well as the rest of the family members.

Implications

The purpose of this study was to develop a theory that represents the experience of fathers living with advanced cancer while raising minor children. The findings discussed the barriers the participants faced and the protective strategies they employed to forge resilience in the midst of a life-threatening disease. The findings indicate this process of resilience was an ongoing challenge for these fathers that ebbed and flowed throughout their cancer experience thus far. These findings address a critical gap in the parental cancer literature by contributing the voice of fathers living with advanced cancer while parenting young children that can have valuable implications in the arenas of practice, research and policy.

Practice implications. Understanding what contributes to resilience in fathers diagnosed with a life-threatening disease such as advanced cancer while raising young children has important implications for social workers and other professionals who work with this population. Recognizing the barriers the participants faced and protective strategies utilized in their efforts to navigate their cancer experience as fathers of young children can inform the development and implementation of supportive services. First and foremost, it is widely accepted in the literature that cancer is a family disease and the findings of this study add further support to this perspective. These fathers recognized the impact this disease experience was having on their children and their spouses. Too often supportive interventions created for people living with cancer do not take a systems approach. Thus, mental health clinicians, and other health professionals working with this

population need to make certain they consider the whole family as they shape their intervention decisions.

The overlapping physical, emotional, financial, and spiritual needs of this population necessitates a transdisciplinary approach where all entities are communicating with one another in their work with families facing cancer. For example, understanding the enormous disruption intractable pain has in the life of these fathers and the ripple effect it had on their families illuminates the importance of working with fathers and their health care team to manage that pain while recognizing families may be particularly vulnerable to distress during these points along the cancer continuum. Additionally, appreciating the link between financial hardship and psychosocial vulnerability among the participants who described their primary role as provider is a critical finding of this study and is supported in the literature (Ceilleachair, et al., 2012; Sharp, Carsin & Timmons, 2013). In the case of several of the participants in this study, ever-depleting funds threatened their ability maintain their residence and at times made it necessary for them to make choices between buying food or making a mortgage payment. The findings of this study highlight the critical importance of understanding how the financial burdens associated with a life-threatening disease such as advanced cancer can impact not only those diagnosed but their family as well. Practice professionals can include assessing the level of financial strain experienced by a family that goes beyond the functional needs and includes the psychosocial impact.

These findings also offer insight into what type of psychosocial support fathers living with advanced disease might accept more readily. For example, all of these fathers

were deeply concerned about how this experience was impacting their children and indicated a readiness to seek and accept support if it would help their children.

Additionally, a number of fathers expressed a concern for the well-being of their spouses and a desire to find support for them. Yet, several expressed hesitation about seeking psychosocial support. An important strength of social work practice is the emphasis on starting where the “client” is at. If these fathers are hesitant to seek psychosocial help when it is presented strictly as emotional support then perhaps instead of changing the men to fit this model of support perhaps we might reshape the model to fit the needs of the fathers as they perceive them initially. For example, offering group education opportunities that are designed to address the practical questions and concerns of participants. A family-oriented psychosocial support intervention could ease those fathers who are reluctant to acknowledge their need for support or have difficulty accepting help by appealing to their desire to help the whole family throughout the cancer experience.

At many points in time, uncertainty cast an enormous cloud over the daily life of these fathers which they perceived had a ripple effect on the family. Walsh’s Family Resilience Theory and Boss’ Ambiguous Loss theory offer guidance for how to work with both the fathers and their families to learn to adapt and live well in the “mystery” of life with cancer. Both theories offer a systems oriented lens to steer practitioners in their relationships with this cohort. The findings indicate that Ambiguous Loss theory might be more informative when working with the families of these fathers. While the fathers were experiencing ambiguity and loss they themselves were the primary object of the ambiguous loss for their families.

Understanding how these participants used various protective factors offers insight into how fathers and consequently their families might build resilience throughout the cancer experience. For example, by being flexible in their expectations of role, being open and honest in their communication, and supporting their attempts to find hope and meaning that is grounded in the reality of the experience (not merely the statistics). Often people diagnosed with advanced cancer can find hope to be elusive if it is defined simply as a hope for a cure. These findings suggest that these fathers were able to broaden their definition of hope to include a desire for more time with their family. Their acute awareness of their limited time motivated them to use that time deepen their relationships with those around them especially their children. These findings can help practitioners shape definitions of hope in the face of a life-threatening disease that supports the resilience process.

Oncology social workers and health professionals have many opportunities along the cancer trajectory to shape the experience of people living with cancer in a way that enables those individuals and their families to build resilience in the face of this disease. Recognizing the barriers and the protective strategies families use to navigate them in the face of a parental diagnosis of advanced cancer can shape practice, research and policy and positively alter the impact of the disease. These findings add to that knowledge base.

Research implications. Given the very limited attention this population has received, there are enormous opportunities for future research that would advance our understanding of the experiences of fathers facing cancer. More research that focuses on the impact of a cancer diagnosis on the experience of fathers raising young children is

critical especially in light of the changing norms of fatherhood that are increasing and broadening a father's involvement in child care tasks. In addition, as cancer treatments have become more sophisticated increasing the life span of those diagnosed with cancer, more studies examining the impact of advanced disease on a family with young children is necessary. Several of the fathers in this study are living with diseases that are not curable but are considered treatable. Thus these participants have lived with cancer as a chronic disease that flares up on occasion requiring them to return to treatment. The episodic nature of this type of cancer can cause a family to have to adjust to multiple and often unpredictable disruptions across their life span (Rolland, 1996). Gaining insight into what supports these families need is crucial. Longitudinal designs could better examine how individuals and their families navigate this disease overtime and intervention research could identify what supports are feasible and effective in this era of diminishing resources.

The findings of this study can inform the design of research studies examining interventions with this population. For example, studies could investigate what interventions support the various pathways of resilience or what factors might further exacerbate the financial strains or other identified barriers.

A cancer diagnosis impacts individuals and their families across all aspects of their life. A transdisciplinary approach to research is another opportunity that could produce valuable information on parental cancer, especially an approach that includes an economic perspective. We know very little about the true cost of cancer yet these findings suggest they are considerable especially when living with a diagnosis of

advanced cancer. Research is needed that examines all the costs associated with the diagnosis and treatment, including all related out-of-pocket costs such as paying for gas, or over-the-counter palliative remedies, or child care. In addition, it is critical that we gain a clearer picture of the costs associated with lost wages. Understanding the financial impact especially in the face of an advanced cancer diagnosis and in the context parental responsibility could shape the designs of future intervention and in turn inform policy as well.

Research that examines the resilience of families from across cultures, ethnicities, races, geographies, and socioeconomic backgrounds is important. As well as examining the experience of families who are structured in various ways including single parent households, blended households, households that are headed by parents of the same sex or by grandparents. Each of these families may experience a parental cancer diagnosis in a unique way requiring differing strategies for resilience.

Finally, it would be very helpful to have a clearer understanding as to how many families are navigating life with a parental cancer diagnosis while raising minor children. While Weaver and colleagues (2010) shed some light on these numbers however, to date theirs is the only population-based study examining the prevalence of this condition. Moreover, most hospitals do not track this data making it difficult to design supportive interventions.

Policy implications. The findings of this study suggest the financial challenges faced by these participants resulted in enormous distress that for some fathers was not alleviated by the level of financial support they received from money given by family and

friends or Social Security Disability Insurance or other small private grants. Several fathers reported a desire to work at a reduced level yet were unable to primarily because they risked losing their public benefits. Walsh (2006) suggests European countries may offer work, disability and family policies that could guide the development of US policies in the context of a cancer experience. Studies examining the cancer-related supportive policies in various countries would be beneficial.

In addition to disability policies, it is important to examine the impact of work-family policies and how they support or impede fatherhood in the US particularly in the context of a life-threatening disease. In a very thoughtful paper entitled *Fatherhood and Equality: Reconfiguring Masculinities*, law professor Nancy Dowd (2012) posits that current US work-family policies diminish fatherhood while supporting hegemonic masculinities. She notes that contrary to other industrialized nations, US policies offer little or no support for family leave and no entitlement leave for the individual worker facing their own disease experience. For example, the Family Medical Leave Act (FMLA) provides only 12 weeks unpaid leave on an annual basis. Illness-related leave varies by state as it is not mandated by the federal government. A critical review of how these policies might be shaped to better support families living with advanced parental cancer is needed.

It bears repeating that each of these fathers had health insurance. It is clear from these findings that without proper health insurance, each of these fathers would have faced financial ruin. Moreover, given the gravity of their prognosis it is likely that the financial burden would be shouldered by their families if they were to pass away. The

cross-sectional nature of this study makes it difficult to draw conclusions about whether these fathers will be able to maintain their insurance coverage over time. For the fathers who had employer-based insurance coverage there was deep concern about what a potential and likely job loss would mean for their future. It is critical that people diagnosed with cancer, especially advanced cancer, have access to affordable health care that is not tied to their employment status.

While it is possible these fathers' experience with financial hardship as a result of their cancer diagnoses is isolated, the larger body of literature coupled with my years of practice experience would indicate otherwise. Clearly a better understanding of the economic burden of cancer on family functioning is needed. Several of these fathers hadn't been working in their careers long enough to develop a savings substantial enough to provide an adequate safety net. It simply is not feasible to plan for this type of financial strain this early in one's life as a parent. It is critical that families with young children are not simply expected to be resilient in the face of tremendous emotional, physical and financial hardship without considering the public policies that could be changed and improved in a manner to better address the impact of this disease on these fathers and their families. As Walsh (2006) states:

We must be cautious that the concept of family resilience not be misused to blame families that are unable to rise above harsh conditions by simply labeling them as not resilient. Just as individuals need supportive relationships to thrive, families require social and institutional policies and programs that foster their ability to rebound and rebuild after major crises and to thrive in the face of prolonged challenges. It is not enough to help families overcome the odds; professionals must also work to change the odds. (p. 136).

Conclusion

This investigation focused on the experiences of fathers living with advanced cancer while raising young children with particular attention paid to the barriers participants had to navigate and the strategies they used that facilitated their resilience in the midst of enormous uncertainty. The present findings add an important perspective to the parental cancer literature – the voice of fathers living with advanced cancer. In addition, this study included fathers from a wide range of socioeconomic levels expanding the literature which has tended to focus primarily on parents of middle to upper socioeconomic class.

In the initial stages of this investigation I wasn't sure if I would find resilience as it has been conceptualized even in the most nuanced terms. As an oncology social worker in a community setting I have certainly seen how living with advanced cancer can ravage a person's body and spirit and derail both a father and his family from a healthy developmental trajectory. I have personally and professionally witnessed the near absence of resilience. That was not the case in the cohort of fathers who participated in this study. Uncertainty, pain, and hardship peppered their experiences as these fathers teeter-tottered between hope and despair striving to live and parent in that place of hope. These fathers exemplified resilience in the face of adversity and their resilience in the face of this extraordinary and ongoing challenge must be acknowledged. A description of fathers' resilience in the face of this disease is offered that may provide fathers living with cancer and the professionals who work with them a conceptual framework to strengthen both the fathers and their families.

References

- Achenbach, T., McConaughy, S., & Howell, C. (1987). Child/adolescent behavioral and emotional problems: Implications of cross-informant correlations for situational specificity. *Psychology Bulletin*, 101(2), 213-232.
- American Cancer Society (2010). *Cancer Facts and Figures - 2010*. Atlanta, GA: American Cancer Society.
- Arendell, T. (1997). Reflections on the researcher-researched relationship: A woman interviewing men. *Qualitative Sociology*, 20(3), 341-346.
- Ashurst, K. (2007). Okay this is my life: A grounded theory study of late adolescent psychosocial experience at the interface of coping with parental cancer. *Dissertation Abstracts International Section A: Humanities and Social Sciences*. 68(4A).
- Babbie, E. (2007). *The Practice of Social Research*. 11th ed. Belmont, CA: Thompson Wadsworth.
- Balboni et. al. (2007). Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *Journal of Clinical Oncology*, 25, 555-560.
- Barnes, J. Kroll, L., Burke, O., Lee, J., Jones, A., Stein, A. (2000). Qualitative interview study of communication between parents and children about maternal breast cancer. *Br Med J*, 321, 479-482.
- Barnes, J. Kroll, L., Lee, J., Burke, O. Jones, A., Stein, A.(2002). Factors predicting communication about the diagnosis of maternal breast cancer to children. *J Psychosom Res*, 52, 209-15.
- Beauchamp, T., & Childress, J. (2001). *Principles of biomedical ethics*. 5ed. Oxford: Oxford University Press.
- Billhut, A. & Segesten, K. (2003). Strength of motherhood: Non-recurrent breast cancer as experienced by mothers with dependent children. *Scandinavian Journal of Caring Science*, 17, 122-128.
- Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief*. Cambridge, MA: Harvard University Press.
- Boss, P. (2006). *Loss, Trauma, and Resilience: Therapeutic work with ambiguous loss*. New York, NY: W.W. Norton & Company.

- Boss, P. (2007). Ambiguous loss theory: Challenges for scholars and Practitioners. *Family Relations*, 56, 105-111.
- Boss, P. (2013). Resilience as tolerance for ambiguity. In D.S. Becvar (Ed.), *Handbook of family resilience* (pp. 285-296). New York: Springer.
- Bradley, C., Neumark, D., Luo, Z., Bednark, H., & Schenk, M. (2005). Employment outcomes of men treated for prostate cancer. *Journal of the National Cancer Institute*, 97, 958-65.
- Brandstatter, M., Baumann, U., Borasio, G., & Fegg, M. (2012), Systemic review of meaning in life assessment instruments. *Psycho-Oncology*, 21, 1034-1052.
- Cabrera, N., Tamis-LeMonda, C., Bradely, R., Hofferth, S. & Lamb, M. (2000). Fatherhood in the twenty-first century, *Child Development*, 71(1), 127-136.
- Ceilleachair, A., Costello, L., Finn, C., Timmons, A., Fitzpatrick, P., Kapur, K., Staines, A., Sharp, L. (2012). Inter-relationship between the economic and emotional consequences of colorectal cancer for patients and their families: A qualitative study. *BMC Gastroenterology*, 12, 62-72.
- Charmaz, K. (1990). Discovering Chronic Illness: Using grounded theory. *Social Science Medicine*, 30(11), 1161-1172.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage.
- Christ, G., & Christ, A., (2006). Current approaches to helping children cope with a parent's terminal illness. *CA Cancer Journal for Clinicians*, 56, 197-212.
- Compas, B.E., Worsham, N., Epping-Jordan, J., Grant, K., Mireault, G., Howell, D., & Malcarne, V. (1994). When mom or dad has cancer: Markers of psychological distress in cancer patients, spouses, and children. *Health Psychology*, 13(6), 507-515.
- Compas, B.E., Worsham, N., Ey, S., & Howell, D. (1996). When mom or dad has cancer: II. Coping, cognitive appraisals, and psychological distress in children of cancer patients. *Health Psychology*, 15(3), 167-175.
- Connell, R. & Messerschmidt, J. (2005). Hegemonic masculinity: Rethinking the concept. *Gender and Society*, 19, 829-859.

- Corbin, J. & Strauss, A. (2008) *Basics of Qualitative Research*. Los Angeles: Sage Publications.
- Coyne & Tennen, (2010). Positive Psychology in Cancer Care: Bad Science, Exaggerated Claims, and Unproven Medicine. *Annals of Behavioral Medicine*, 39(1): 16–26.
- Cusack, J., Deane, F., Wilson, C. & Ciarrochi (2004). Who influences men to go to therapy? Reports from men attending psychological services. *International Journal for the Advancement of Counseling*, 26(3), 271-283).
- Daly, K. (2007). *Qualitative methods for family studies and human development*. Los Angeles: Sage Publications.
- Davey, M., Asker, J., & Godette, K. (2003). Parent and adolescent responses to non-terminal parental cancer: A retrospective multiple-case pilot study. *Families, Systems, and Health*, 21, 245-258.
- Davey, M., and Davey, A (2005). Adolescents coping with non-terminal parental cancer. *The Prevention Researcher*, 12(4), 7-9.
- DeHaan, Hawley & Deal, (2013). Operationalizing family resilience as process: Proposed methodological strategies. In A. Goldstein, & R. Brookes, (Eds.), *Handbook of resilience in children* (pp.17-29). New York: Springer.
- Denzin, N., and Lincoln, Y. (Ed.). (2000). *Handbook of qualitative research*. (2nd Ed.). Thousand Oaks, CA: Sage.
- Dickson-Swift, V., James, E., & Liamputtong, P. (2008). *Understanding sensitive research in the health and social sciences: Managing boundaries, emotions, and risks*. New York: Cambridge University Press.
- Dowd, N. (2012). Fatherhood and Equality: Reconfiguring masculinities. *Suffolk University Law Review*, 45(4). Available at SSRN: <http://ssrn.com/abstract=2199556>
- Drageset, S., Lindstrøm, T., & Underlid, K. (2010). Coping with breast cancer: Between diagnosis and surgery. *Journal of Advanced Nursing*, 66(1), 149-158.
- Dubois, B., and Miley, K. (1999). *Social Work: An Empowering Profession*. (3rd ed.) Needham Heights, MA: Allyn and Bacon.
- Dunning, S. (2006). As a young child's parent dies: conceptualizing and constructing preventative interventions. *Clinical Social Work Journal*, 34(4), 499-513.

- Edwards, B., & Clarke, V. (2004). The psychological impact of a cancer diagnosis on families: The influence of family functioning and patients' illness characteristics on depression and anxiety. *Psycho-Oncology*, 13, 562-576.
- Erikson, E. H. & Erikson, J. M. (1998). *The life cycle completed: A review*. New York: Norton, W.W. & Company, Inc.
- Elmberger, E., Bolund, C., & Lutzen, K. (2002). Men with cancer: Changes in attempts to master self-image as a man and as a parent. *Cancer Nursing*, 25(6), 477-485.
- Faulkner, R.A., & Davey, M. (2002). Children and adolescents of cancer patients: The impact of cancer on the family. *American Journal of Family Therapy*, 30, 63-72.
- Finlay, L. (2002). Outing the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research*, 12, 531 – 545.
- Fitch, M., Bunston, T., & Elliot, M. (1999). When mom's sick: Changes in a mother's role and in the family after her diagnosis of cancer. *Cancer Nursing*, 22(1), 58-63.
- Folkman, S. & Lazarus, R. (1988). The relationship between coping and emotion: Implications for theory and research, *Social Science Medicine*, 26, 309-317.
- Frankl V. (1997). *Man's Search for Ultimate Meaning*. New York, NY: Plenum Press.
- Garnezy, N. (1993). Children in poverty: Resilience despite risk. *Children and Violence*, 56(1), 127-137.
- Germino, B., Mishel, M., Belyea, M., Harris, L., Ware, A., Mohler, J. (1998). Uncertainty in prostate cancer: Ethnic and family patterns. *Cancer Practice*, 6 (2), 107-113.
- Glaser, B. & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New Brunswick: Aldine.
- Gilgun, J. (1994). Hand into Glove. In E. Sherman & W. J. Reid (Eds). *Qualitative research in social work* (pp.115-125). New York: Columbia University Press.
- Gilgun, J. (2005). "Grab" and good science: Writing up the results of qualitative research. *Qualitative Health Research*, 15, 2, 256-262.
- Gilgun, J. (2011). Reflexivity and qualitative research. *Current Issues in Qualitative Research*, 1(2) retrieved from <http://www.smashwords.com>

- Grant, K., & Compas, B.E. (1995). Stress and anxious-depressed symptoms among adolescents: Searching for mechanisms of risk. *Journal of Consulting and Clinical Psychology*, 63(6), 1015-1021.
- Gray, R., Fitch, M., Phillips, C., Labrecque, M., & Fergus, K. (2000a). Managing the impact of illness: The experiences of men with prostate cancer and their spouses. *Journal of Health Psychology*, 5, 531-48.
- Gray, R., Fitch, M., Phillips, C., Labrecque, M., & Fergus, K. (2000b). To tell or not to tell: Patterns of disclosure among men with prostate cancer. *Psycho-Oncology*, 9, 273-282.
- Grbich, C. (2007). *Qualitative Data Analysis: An introduction*. London: Sage Publications.
- Greening, K. (1992). The bear essentials' program: Helping children and their families cope when a parent has cancer. *J Psychosoc Oncology*, 10, 47-61.
- Haisfield-Wolfe, M., McGuire, D., Soeken, K., Geiger-Brown, J., De Forge, B., Suntharalingam, M. (2012). Prevalence and correlates of symptoms and uncertainty in illness among head and neck cancer patients receiving definitive radiation with or without chemotherapy. *Support Care Cancer*, 20, 1885-1893.
- Hamilton, R., Miedema, B., MacIntyre, L., & Easley, J. (2011). Using a positive self-talk intervention to enhance coping skills in breast cancer survivors: Lessons from a community-based group delivery model. *Current Oncology*, 18(2), 46-53.
- Hardy, J. (2006). Speaking clearly: A critical review of self-talk literature. *Psychology of Sport and Exercise*, 7, 81-97
- Hartling, L. (2003). Strengthening resilience in a risky world: It's all about relationships. Speech at Stone Center at Wellesley College, Wellesley, MA.
- Harris, C., & Zakowski, S. (2003). Comparisons of distress in adolescents of cancer patients and controls. *Psycho-Oncology*, 12: 173-182.
- Helseth, S. & Ulfsest, N. (2005). Parenting experiences during cancer. *Journal of Advanced Nursing*, 52(1), 38-46.
- Himmelstein, D. Thorne, D. Warren, E., & Woolhandler, S. (2009). Clinical Significance Medical Bankruptcy in the United States, 2007: Results of a National Study *The American Journal of Medicine*, 122(8), Pages 741-746

- Hoke, L. A short-term psychoeducational intervention for families with parent cancer. *Harv Rev Psychiatry*, 5, 99-103
- Hoke, L. (2001). Psychological adjustment in children of mothers with breast cancer. *Psycho-Oncology*, 10, 361-369.
- Hope, R., & Hodge, D. (2006). Factors affecting children's adjustment to the death of a parent: The social work professional's viewpoint. *Child and adolescent Social Work Journal*, 23(1), 107-126.
- Howes, M., Hoke, L., Winterbottom, M. & Delafield, D. (1994). Psychosocial effects of breast cancer on the patient's children. *Psycho-Oncology*, 12(4), 1-21.
- Huizinga, G., Visser, A., Van der Graaf, W., et al. (2005). Stress response symptoms in adolescent children of parents diagnosed with cancer. *European Journal of Cancer*, 41, 288-295.
- Hymovich, D. (1993). Child-rearing concerns of parent with cancer. *Oncology Nursing Forum*, 20, 1355-60.
- IOM (Institute of Medicine). (2004). *Meeting psychosocial needs of women with breast cancer*. Washington DC: The National Academies Press.
- IOM (Institute of Medicine). (2007). *Cancer Care for the Whole Patient: Meeting the psychosocial health needs*. Washington DC: The National Academies Press.
- Ivanova, M., Achenbach, T., Dumenci, L., Rescola, L., Weintraub, S., Bilenberg, N., et al. (2007). Testing the 8-syndrome structure of the child behavior checklist in 30 societies. *Journal of Clinical Child and Adolescent Psychology*, 36,(3), 405-417.
- Kaiser Health Tracking Poll, Jul, 2010. Retrieved May-31-2011 from the iPOLL Databank, The Roper Center for Public Opinion Research, University of Connecticut.
http://www.ropercenter.uconn.edu.ezp2.lib.umn.edu/data_access/ipoll/ipoll.html
- Kalter, N., Lohnes, K., Chasin, J., Cain, A., Dunning, S., Rowan, J. (2002). The adjustment of parentally bereaved children: I. Factors associated with short-term adjustment. *Omega*, 46(1) 15-34.
- Kennedy, V., Lloyd-Williams, M. (2009). Information and communication when a parent has advanced cancer. *Journal of Affective Disorders*, 114, 149-155.
- Kirsch S., Brandt, P., & Lewis, F. (2003). Making the most of the moment: when a child's mother has breast cancer. *Cancer Nursing*, 26, 47-54.

- Kotchick, B., Forehand, R., Armistead, L., Klein, K., Wierson, M. (1996). Coping with illness: Interrelationships across family members and predictors of psychological adjustment. *Journal of Family Psychology*, v0(3), 358-370.
- Kroll, L., Barnes, J., Jones, A., & Stein, A. (1998). Cancer in parents: Telling children. *British Medical Journal*, 316, 880-880.
- Lagnado, L. (2008, October 4). In some cultures, cancer stirs shame. *The Wall Street Journal*, p. A1. Retrieved April, 2011 from <http://online.wsj.com/article/SB122304682088802359.html>
- Lazarus, R. (2000). Toward better research on stress and coping. *American Psychologist*, 55(6), 665-673.
- Lewis, F., & Darby, E. (2003) Adolescent adjustment and maternal breast cancer: A test of the faucet hypothesis. *Journal of Psychosocial Oncology*, 21(4) 81-104.
- Lewis, F. (2007). Parental cancer and dependent children: selected issues for future research. *Psycho-Oncology*, 16, 97-98.
- Leung, P., Kwong, S.L., Tang, C.P., Ho, T.P., Hung, S. F., Lee, C.C., Hong, S.L., Chiu, C.M., Liu, W.S. (2005). Test-retest reliability and criterion validity of the Chinese version of CBCL, TRF, and YSR. *Journal of Child Psychology and Psychiatry*, 47(9), 970-973.
- Lincoln, Y.S. & Guba, E.G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage Publications.
- MacPherson, C. (2005). Telling children the ill parent is dying: A study of the factors influencing the well parent. *Mortality*, 10(2), 113-126.
- Masten, A., Best, K., & Garmezy, N. (1990). Resilience and development: Contributions from the study of children who overcame adversity. *Development and Psychopathology*, 2, 425-444.
- McCubbin, H. & McCubbin, M. (1988). Typologies of resilient families: Emerging roles of social class and ethnicity. *Family Relations*, 37(3), 247-254.
- McCubbin, H. I., & Patterson, J. M. (1983a). The family stress process: The double ABCX model of adjustment and adaptation. *Marriage and Family Review*, 6 (1/2), 7-37.

- Mcperson, K. & Leydon, G. (2002). Quantitative and qualitative methods in UK health research: then, now and ...? *European Journal of Cancer Care*, 11(3), 225-231.
- Meropol, N., Schragg, D., Smith, T., Mulvey, T., Langdon, R., Blum, D., Ubel, P. & Schnipper, L. (2009). American society of clinical oncology guidance statement: the cost of cancer care. *Journal of Clinical Oncology*, 27(23), 3838-3874.
- Mishel, M., & Braden, C. (1988). Finding Meaning: Antecedents of uncertainty in illness. *Nursing Research*, 37(2), 98-127.
- Moore, Christine (2005). Impact of humor on patients with cancer. *Clinical Journal of Oncology Nursing*, 9(2), 211-218.
- Mori, M., Elsayem, A., Reddy, S., Bruera, E., Fadul, N. (2012). Unrelieved pain and suffering in patients with advanced cancer. *American Journal of Hospice and Palliative Medicine*, 29(3), 236-240.
- Morse, J. (2000). Researching illness and injury: Methodological considerations. *Qualitative Health Research*, 10(4), 538-546.
- Moynihan, C. (2002). Men, women, gender and cancer. *European Journal of Cancer*, 11, 166-172.
- National Cancer Institute: FactSheet on Cancer Staging Retrieved on Dec. 12, 2009 from <http://www.cancer.gov/cancertopics/factsheet/Detection/staging>
- National Cancer Institute: Surveillance Epidemiology and End Results. Retrieved on Dec. 3, 2009 from <http://seer.cancer.gov/faststats/selections.php#Output>.
- Nelson, E., Sloper, P., Charlton, A., While, D. (1994). Children who have a parent with cancer: A pilot study. *Journal of Cancer Education*, 9(1), 30-36.
- Neville, K. (2003). Uncertainty in illness. *Orthopaedic Nursing*, 22(3), 206-214.
- Nicholas, D. (2000). Men, masculinity, and cancer: Risk-factor behaviors, early detection, and psychosocial adaptation. *Journal of American College Health*, 49, 27-33.
- Northouse, L., Mood, D. Kershaw, T., Schafenacker, A., Mellon, S., Walker, J., Galvin, E., & Decker, V. (2002). Quality of life of women with recurrent breast cancer and their family members. *Journal of Clinical Oncology*, 20(19), 4050-4064.

- O'Brien, R., Hunt, K., Hart, G. (2005). 'It's caveman stuff, but that is to a certain extent how guys still operate': Men's accounts of masculinity and help seeking. *Social Science and Medicine*, 61, 503-516.
- Oktaý, J. (2012). *Grounded Theory*. New York: Oxford University Press: New York.
- Oliffe, J., Ogrodniczuk, J., Botorff, J., Hislop, G., & Halpin, M. (2009). Connecting humor, health, and masculinities at prostate cancer support groups. *Psycho-Oncology*, 18, 916-926.
- O'Neil, J. (2008). Men's gender conflict: 25 years research summary [Special issue]. *The Counseling Psychologist*, 36, 358-476.
- O'Neill, C., McCaughan, E., Semple, C. & Ryan, A. (2013). Fatherhood and cancer: a commentary on the literature. *European Journal of Cancer Care*, 22(2), 161-168
- Osborn, T. (2007). The psychosocial impact of parental cancer on children and adolescents: a system review. *Psycho-Oncology*, 16, 101-126.
- Parker, K. & Wang, W. Modern parenthood: Roles of moms and dads converge as they balance work and family. Pew Research Center, March 14, 2013, http://www.pewsocialtrends.org/files/2013/03/FINAL_modern_parenthood_03-2013.pdf, Accessed on March 16, 2013.
- Patenaude, A. (2000). A different normal: reactions of children and adolescents to the diagnosis of cancer in a parent. In L. Baider, C. Cooper, & A. De-Nour (Eds.), *Cancer and the family* (239-254). West Sussex: John Wiley & Sons, LTD.
- Patterson, J. (2002). Understanding family resilience. *Journal of Clinical Psychology*, 58(3), 233-246.
- Patton, M. (2002). *Qualitative research and evaluation methods* (3rd Ed.). Thousand Oaks, CA: Sage.
- Reynolds, C. and Richmond, B. (1985). *Revised Children's Manifest Anxiety Scale (RCMAS) Manual*. Los Angeles: Western Psychological Services.
- Richardson, G. (2002). The metatheory of resilience and resiliency. *Journal of Clinical Psychology*, 58(3), 307-321.
- Ridge, D., Emslie, C., & White, A. (2011). Understanding how men experience, express and cope with mental distress: Where next? *Sociology of Health and Illness*, 33(1), 145-159.

- Rolland, J. (1994). *Families, Illness, and Disability*. New York: HarperCollins.
- Rolland, J.S. (2005). Cancer and the family: An integrative model. *Cancer*, 104(11sup), 2584-2595.
- Rose, J., Kypriotakis, G., Bowman, K., Einstadter, D., O'Toole, E., Mechekano, R., & Dawson, N. (2009). Patterns of adaptation in patients living long term with advanced cancer. *Cancer*, 115(S18), 4298- 4310.
- Rosenblatt, P. (1995). Ethical of qualitative interviewing with grieving families. *Death Studies*. 19, 139-155.
- Rosenheim, E. & Reicher, R. (1985). Informing children about a parent's terminal illness. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 6, 995-998.
- Rosenheim, E. & Reicher, R. (1986). Children in anticipatory grief: The lonely predicament. *Journal of Clinical Child Psychology*, 15(2), 115-119.
- Rowland, J. & Baker, F (2005). Introduction: Resilience of cancer survivors across the lifespan. *Cancer*, 104(S11) 2543-2548.
- Rutter, M. (2012). Resilience as a dynamic concept. *Developmental and Psychopathology*, 24, 335-344.
- Saldinger, Amy, Porterfield, K., and Cain, A. (2004). Meeting the needs of parentally bereaved children: A framework for child-centered parenting. *Psychiatry*, 67(4), 331-352.
- Sarkadi, A., Kristiansson, R., Oberklaid, F. & Bremberg (2008). Father's involvement and children's developmental outcomes: A systematic review of longitudinal studies. *Acta Paediatrica*, 97, 153-158.
- Semple, C. & McCance, T. (2010). Experience of parents with head and neck cancer who are caring for young children. *Journal of Advanced Nursing*, 66(6), 1280-1290.
- Semple, C. & McCance, T. (2010b). Parents' experience of cancer who have young children. *Cancer Nursing*, 33(2), 110-118.
- Shaha, M., Cox, C., Talman, K., & Kelly, D. (2008). Uncertainty in breast, prostate, and colorectal cancer: Implications for supportive care. *Journal of Nursing Scholarship*, 40(1), 60-67.
- Shands, M., Lewis, F., & Zahlis, E. (2000). Mother and child interactions about the mother's breast cancer: An interview study. *Oncol Nurs Forum*, 27, 77-85.

- Sharp, L., Carsin, A., & Timmons, A. (2013). Associations between cancer-related financial stress and strain and psychological well-being among individuals living with cancer. *Psycho-Oncology*, 22, 745-755.
- Sheehan, D., & Draucker, C. (2011). Interaction patterns between parents with advanced cancer and their adolescent children. *Psycho-Oncology*, 20(10), 1108-1115.
- Siegel, R. et al., (2012). Cancer treatment and survivorship statistics. *CA a cancer journal for clinicians*, 62(4), 220-241.
- Siegel K., Mesagno, F., Karus, D., Christ, G., Banks, K., Moynihan, R. (1992). Psychosocial adjustment of children with a terminally ill parent. *Journal of American Academy of Child Adolescent Psychiatry*, 31(2), 327-333.
- Stiffler, D. Haase, J., Hosei, B., Barada, B. (2008). Parenting experiences with adolescent daughters when mothers have breast cancer. *Oncology Nurse Forum*, 35(1), 113-120.
- Swick, S., & Rauch, P. (2006). Children facing the death of a parent: The experiences of a parent guidance program at the Mass General hospital cancer center. *Child and Adolescent Psychiatry Clin N Am*, 15, 779-794.
- Taylor-Brown, J. Acheson, A. Farber, J. (1993). Kids can cope: A group intervention for children whose parents have cancer. *J Psychosoc Oncology*, 11, 41-53.
- Teunissen, S., Wesker, W., Kruitwagen, C., de Haes, H., Voest, E., & de Graeff, A. (2007). Symptom prevalence in patients with incurable cancer: A systematic review. *Journal of Pain and Symptom Management*, 34 (1), 94-104.
- Vannatta, K., Grollman, J., Noll, R., & Gerhardt, C. (2008). Impact of maternal breast cancer on the peer interactions of children at school. *Psycho-Oncology*.
- Veach, T., & Nicholas, D. (1998). Understanding families of adults with cancer: Combining the clinical course of cancer and stages of family development. *Journal of Counseling and Development*, 76, 144-156.
- Visser, A., Huizinga, G., van der Graaf, W., Hoekstra, H., & Hoekstra-Weebers, J. (2004). *Cancer Treatment Reviews*, 30, 683-694.
- Visser, A., Huizinga, G., Hoekstra, H., & van der Graaf, W. (2007). Temperament as a predictor of internalizing and externalizing problems in adolescent children of parents diagnosed with cancer. *Supportive Care in Cancer*, 15(4), 395-403.

- Walsh-Burke, K. (1992). Family communication and coping with cancer: Impact of the We Can Weekend. *Journal of Psychosocial Oncology*, 10(1), 63-81.
- Walsh, D., Donnelly, S., Rybicki, L. (2000). The symptoms of advanced cancer: Relationship to age, gender, and performance status in 1,000 patients. *Support Care Cancer*, 8, 175-179.
- Walsh, F. (2006) *Strengthening Family Resilience* (2nd ed.). New York: The Guildford Press.
- Walsh, S., Manuel, J. Avis, N. The impact of breast cancer on younger women's relationships with their partner and children. *Family Systems Health*, 23(1), 80-93.
- Ward, E., Jemal, A., Cokkinides, V., Singh, C. (2004). Cancer disparities by race/ethnicity and socioeconomic status. *CA: A Cancer Journal for Clinicians*, 54, 78-95.
- Weaver, K., Rowland, J., Alfoan, C., & McNeel, T. (2010). Parental cancer and the family. *Cancer*, 116(18), 4395-4401.
- Welch, A.S., Wadsworth, M.E., & Compas, B.E. (1996). Adjustment of children and adolescents to parental cancer. *Cancer*, 77(7), 1409-1418.
- Wright, M., Masten, A. & Narayan, A. (2013). Resilience processes in development: Four waves of research on positive adaptation in the context of adversity. In A. Goldstein, & R. Brookes, (Eds.), *Handbook of resilience in children* (pp.15-37). New York: Springer.
- Yabroff, K., Lawrence, W., Clauser, S., Davis, W., and Martin L. Brown, M. (2004). Burden of illness in cancer survivors: Findings from a population-based national sample. *Journal of the National Cancer Institute*, 96, 1322-30.
- Zabalegui, A. (1999). Coping strategies and psychological distress in patients with advanced cancer. *Oncology Nursing Forum*, 26(9):1511-8
- Zabora, J., BrintzenhofeSzoc, K., Curbow, B., Hooker, C. & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psycho-oncology*, 10, 19-28.
- Zautra, A., Johnson, M. & Davis, C. (2005). Positive affect as a source of resilience for women in chronic pain. *Journal of Consult Clinical Psychology*, 73(2):212-220.

Appendix A: Consent Form
University of Minnesota School of Social Work
Consent for participation in a study titled: Fathers Facing Cancer

WHY AM I BEING INVITED TO TAKE PART IN THIS STUDY?

You are being asked to take part in this research study about the experience of being a father diagnosed with cancer who is parenting young children. You are being invited because you have been diagnosed with either stage 3 or stage 4 cancer and are the father of at least one child aged 18 years or younger. If you take part in this study you will be one of about 25 people to do so. We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this study is to better understand what the experience of being a parent diagnosed with cancer is like for fathers with younger children. The researcher wants to document and write about this experience in order to help other families in similar situations. Currently little is known about how a father's cancer diagnosis impacts his family. It is important to find out about the challenges father's such as yourself face when diagnosed with cancer. The results of this study will help in the design of an education and support program and hopefully reduce some of the strain for families such as yours.

WHERE IS THIS STUDY GOING TO TAKE PLACE?

The research interviews will take place at a location that is convenient for you and the researcher. It can be at your home, in a coffee shop, near your clinic, or in a meeting room at the University of Minnesota Campus. We will also agree on a time and date.

HOW LONG WILL IT LAST?

If you agree to participate you will be asked to meet one time. The interview will last approximately 60 – 90 minutes depending on how long you are able to meet.

WHAT WILL I BE ASKED?

You will be asked to answer questions about your experiences being a father of young children while living with a diagnosis of cancer. The interviews will be audiotaped and, after the interview is over, our information will be compared to other fathers in the study to see what important issues are in the lives in families where the father has cancer.

WHAT ARE THE RISKS OF BEING IN THIS STUDY?

There are some risks to being in this study. Living with a life-threatening disease like cancer can be very difficult to talk about and you may find some questions unsettling. The main potential risk may be that you experience strong emotional reactions about questions related to death. The researcher conducting the study has years of experience working with families such as yours and can refer you to appropriate resources for support.

WHAT ARE THE BENEFITS TO BEING IN THE STUDY?

There is no guarantee that you will benefit from your participation in this study. However, many people who participate in research studies such as these find that they feel a deep sense of satisfaction knowing that they can use their own challenging life experience to help others. In addition, many people with cancer find they feel a sense of relief from talking about their experience to someone else.

WILL THERE BE ANY COSTS FOR ME TO PARTICIPATE?

Other than your time and potentially costs for transportation, there will be no costs to you for taking part in this study.

WILL I RECEIVE ANY PAYMENT?

You will receive a one-time \$25 gift card to cover any costs for transportation and for your time during the interviews. This gift card will be yours to keep even if you decide not to participate.

WHO WILL SEE THE INFORMATION I GIVE?

Your information will be kept private. In any sort of report we may publish, we will not include any information that will make it possible to identify you. All research records will be kept in a locked file. Access to those records will be limited to the researcher. The audio tape recordings will be accessible only to the researcher and will be destroyed immediately after being transcribed onto paper.

WHAT IF I DECIDE I NO LONGER WANT TO PARTICIPATE IN THE STUDY?

Your participation is completely voluntary. If you decide to take part you still have the right to stop participating at any time throughout the study for any reason. There is no penalty for stopping your participation.

WHAT IF I HAVE QUESTIONS?

The researcher conducting this study is Melissa Lundquist. For questions or more information you may contact her by phone at 651-261-4998 or by email at lund1086@umn.edu. If at any time you have questions about your rights as a research participant you may contact: Director, Office for Human Research Participant Protection, University of Minnesota by phone at (612) 626-5654, or by email at irb@umn.edu.

Please keep the enclosed copy of this form for your records and for future reference.

STATEMENT OF CONSENT

I have read (or have had read to me) the contents of this consent form. I have received answers to my questions. I offer my consent to participate in this study.

_____ Date
Study Participant

_____ (initial) I have been provided a copy of this form to keep for my records.

Please sign and return one copy of this form in the postage paid envelope provided. You will be contacted by Melissa Lundquist, the principal researcher, to make sure that you understand the study and to set up a time for the first interview.

Appendix B: Initial Codes

Initial Codes
Change: <ul style="list-style-type: none">• in physical ability• cognitive ability• financial situation• sense of self• dreams for future• sense of children• in role• definition of family• definition of father• priorities• family routine
Fear: <ul style="list-style-type: none">• of pain• of death• of leaving children• of children forgetting them• of leaving spouse/partner• of financial ruin
Support: <ul style="list-style-type: none">• from family• from community• from faith• medical team• type
Communication: <ul style="list-style-type: none">• decisions about who is told of diagnosis• how cancer is talked about within family• how cancer is talked about outside family• how concerns about death are discussed
Meaning: <ul style="list-style-type: none">• how he has made sense of his diagnosis• how children make sense of the cancer• what it means to be a father• what it means to be a man
Uncertainty: <ul style="list-style-type: none">• about diagnosis• about treatment decisions

- about treatment side effects and efficacy
- about survival
- about the future

Source of Codes:

These initial codes are derived primarily from my professional experience. They are also influenced by my personal experience and my knowledge of the literature.

Appendix C: Interview Guide

This list of questions will serve as a guide and not an exact format to which I will adhere. Given the simultaneous nature of data collection and analysis, topics raised in the initial interview will be built into the subsequent interviews. Follow-up questions designed to deepen the shared information will be asked as well as questions deemed necessary for clarification or to inspire further reflection.

Basic Demographic Questions:

- Name
- Age
- Marital status
- Children (names, genders, and ages) (do they reside with you?)
- How would you describe your race or ethnicity?
- Type of cancer (including stage)
- Date of initial (and subsequent if appropriate) diagnosis
- Description of treatment(s)

Initial Open-ended Questions

- Tell me about when you found out you had cancer.
- Can you describe the decisions you made about who to tell? When to tell? How to tell?
- Can you describe what it was like to tell your children?
- Could you describe to me how this diagnosis has impacted your family?
- How do you make sense of your diagnosis?
- How do you think your children make sense of your diagnosis?
- What is like to parent when you have cancer?
- How would you describe your life before your diagnosis?
- How your view of yourself changed?
- How has your definition of fatherhood been impacted?
- How do you talk about the cancer in your family?
- What has been helpful to you throughout this experience?
- What do you think has helped your family?
 - How do you feel you have grown as a result?

Appendix D: Resource List

Resources for Education and Support for Cancer Patients and Families

Community Resources and National Cancer Organizations

- American Cancer Society**.....1800-ACS-2345 or
Provides navigators who assist patients and families with 952-925-2772
emotional support, information about cancer, and referrals to www.cancer.org
support groups in the community. Offers a wig room at the
local ACS office located at
2520 Pilot Knob Road #150, Mendota Heights, MN 55120.
- Angel Foundation** 952-830-0519
Nonprofit organization working to support the unmet medical
www.mnangel.org needs of people touched by cancer including family
education and support programs and financial assistance.
- CancerCare**.....1800-813-4673
A national nonprofit that provides free, professional support
www.cancer.org
services to anyone affected by cancer. Located in New York
City, they offer free online and telephone support groups as
well as educational workshops.
- Kids Konnected**1 800-899-2866
A national resource offering friendship, education, and www.kidskonnected.org
support for kids who have a parent with cancer. Services
include a hotline for kids, educational resources, web site, and summer camps.
- KidsCope**404-892-1437
Information to help children understand the effects of www.kidscope.org/kids.html
cancer treatment Offers the Kemo Shark booklet in English
and Spanish.
- National Cancer Institute** 1 800-4-Cancer
Provides information about cancer, clinical trials, and research. www.cancer.gov
- National Coalition for Cancer Survivorship**1 877-nccs-yes
Educational resources and advocacy for persons with www.canceradvocacy.org
any type of cancer.

- Open Arms** 612-872-1152
 A nonprofit service organization that prepares and delivers meals@openarmsmn.org
 free meals specifically tailored to meet the nutrition needs
 of individuals living with cancer and other serious illness.
- Pathways**..... 612-822-9061
 Health crisis resource center that offers educational www.pathwayminneapolis.org
 programs, support groups, and complementary therapies.
 Pathways provides programs designed to support a creative
 healing response to life threatening illness.
- The Leukemia & Lymphoma Society**763-545-3309
 Recognizes the needs of people with leukemia, lymphoma, www.leukemia-lymphoma.org
 Hodgkin’s lymphoma and myeloma. Provides patient
 services including: First connection peer support program, a family support group,
 patient education programs, and patient financial aid.
- University of Minnesota Cancer Center**612-624-2620
 Cancer information and related services. www.cancer.umn.edu
- Well Spouse Foundation**1 888-838-0879
 Support and resources for spouses of persons with chronic www.wellspouse.org
 illness.
- Well Spouse Support Group**952-938-0617
 Support and resources for spouses of persons with chronic illness.
- Well Within**651-451-3133
 A nonprofit holistic wellness resource center that offers www.wellwithin.org
 classes, creative art exploration, one-on-one sessions, and
 other integrative wellness experiences.

Therapists Who Specialize in Cancer Care

- Brenda Hartman, M.S.W., L.I.C.S.W.**651-697-9981
 Therapy for Children, Adults & Families, Inc.
 Services include outpatient counseling for children, teens, and adults.
 Roseville, MN

- Mary Hughes, M.A., L.P., L.I.C.S.W.** 651-232-7970
 Outpatient counseling for children, teens, and adults.
 Located at St John’s Hospital. Affiliated with HealthEast Cancer Center
- Winifred B. Lilly-Taylor, Ph.D., L.P., C.H.T.P.** 612-929-2421
 Outpatient counseling for adults and healing touch.
 Minneapolis, MN
- Gail Noller and Kathering Michaels** 763-785-8111
 Northtown Psychology Associates
 Outpatient counseling
 Coon Rapids, MN

Additional Counseling and Crisis Resources

- Behavioral Healthcare Providers**763-525-1746 or 1800-361-0491
 Referral information to a network of psychiatrists, psychologists, and therapists who provide mental health and chemical dependency services.
- Burnsville Counseling and Healing Center**952-435-4144
 Outpatient counseling and grief services.
- Center for Grief**651-641-0177
 Seminars, support groups, and therapy groups for children, teens, and adults.
- Crisis Connection**612-379-6363
 24 hour crisis line serving the metro area.
- Growing Through Grief**952-993-6209
 A support program for children from kindergarten through high school who are experiencing or preparing for the death of a loved one. Offered in various schools around the metro area.
- First Call for Help**211
 Referral service to community resources, including counseling, support groups, financial/legal/social concerns.
- Professional Counseling and Grief Services**952-891-2525
 Outpatient counseling and grief support services.
- Sanctuary: A Center for Psychotherapy,**.....651-255-6711
Spiritual Direction and Education

Outpatient counseling and spiritual direction.

Schlutter and Associates952-925-4649
Outpatient counseling.

Note: *The listing of these resources does not imply endorsement by this researcher. Please check with your insurance provider for specific information about benefits and referrals for counseling services.*

Seeking Research Participants

**Study Title: Parenting Through Advanced Cancer
Exploring a Father's Experience**

Study description

Being a father living with advanced cancer while parenting children can be an extraordinary challenge. The purpose of this study is to better understand this experience in order to design services that can help families like yours. If interested you will participate in a 60-90 minute in-person interview. Feel free to contact the researcher with any questions.

Eligibility

If you are an adult male living with cancer and:

1. Are a father of children under the age of 18yrs old
2. Have been diagnosed with any type of cancer
3. Your cancer is stage 3 or 4
4. You speak English

Contact person: Missy Lundquist, doctoral candidate
U of M Department of Social Work
Phone: 651-261-4998
Email: lund1086@umn.edu

Compensation: Participants will be given a \$25 Target gift card for the research participation.