The Lived Experience of Fathers with Advanced Cancer

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THE LIVED EXPERIENCE OF FATHERS WITH ADVANCED CANCER

BY

MARIA MOWASSEE

This dissertation is submitted to the graduate faculty in Nursing
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2016
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This manuscript has been read and accepted for the Graduate Faculty in Nursing in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy

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ABSTRACT

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Historically, fathers have been neglected as a research population in the nursing and oncology literature. This was in relation to their role being viewed as a disciplinarian and breadwinner instead of a nurturer. Fast-forward to modern day society, their role has evolved into a more involved parent that is necessary for their child’s development and well-being. The literature has also evolved and in recent years, this population has been gaining recognition and it is of great importance to understand their role, perception, and concerns as it pertains to being involved fathers. Therefore, when considering fathers with advanced cancer when death is imminent, an urgency and importance to continue research in this population is created. Understanding these fathers is of significant value to them and to the nurses who care for them. The purpose of this qualitative study is to describe and understand the experience of fathers with advanced cancer. Ten fathers were interviewed and shared their experiences. The interviews were analyzed using van Manen’s (1990) phenomenological method and seven themes were uncovered that provided the structure to understand their lived experience. Those themes are, live longer, financial security, making memories, fatherhood, maintaining normalcy, finding strength and support and dealing with challenges. From these themes, the essence of a father’s unconditional and eternal love is described and brought to a close this research study of the lived experience of fathers with advanced cancer.
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To the ten fathers that participated, that willingly and unselfishly shared their struggle and intimate moments, my heart is overwhelmed by your openness and trust. You saw the value in telling your story and I thank you. I will never forget you and will forever be humbled and grateful to you. Your daily courage to live life every day, not knowing when it will be your last and your evident love for your children have both inspired and made me a better person. I dedicate this work to you and your children.

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making me laugh when I wanted to sit in a corner and cry. This process has been a long one and no one will completely understand my struggle, but your presence and support along the way was warmly welcomed and appreciated. Thank you for not allowing me to give up. To Ravi, our lives have taken different paths but I cannot forget you and I will always be thankful for the ways you supported me. I wish nothing but the best for you and your future.
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CHAPTER I: PURPOSE OF THE STUDY

Introduction

If I knew that today is the last time that I am going to see you asleep, I would hug you with all my strength and I would pray to the Lord to let me be the guardian angel of your soul.

If I knew that these are the last moments to see you, I would say “I love you.”

There is always tomorrow, and life gives us another opportunity to do things right, but in case I am wrong, and today is all that is left to me, I would love to tell you how much I love you & that I will never forget you. (Marquez, n.d.).

These are words from the famous Columbian writer and Nobel Peace Price winner for literature, Gabriel Garcia Marquez. He was diagnosed with lymphatic cancer and when he thought his condition had worsened and he was dying, he wrote a farewell poem to his loved ones. The thought of dying stirred within him a desire to express his love for his family and friends. Dying, an inevitable, naturally occurring phenomenon is usually an emotional phase in one’s life and the thought of leaving loved ones behind often forces a person to focus on what truly matters in life. This often revolves around the time, love and memories shared between family and friends. Though saying goodbye to loved ones and leaving a life that you love behind can be challenging, it can sometimes elicit something that is beautiful and positive. The following is such a story about Tim (a pseudonym), a father who knew he was dying but fought to stay alive for his underage children. His desire to live and the deep love he expressed for his children stirred a curiosity and concern within me and it was then I committed my doctoral dissertation to understanding the lived experience of fathers with advanced cancer. My commitment to this topic and phenomenon, one that seriously interests me and commits me to this world is the first step in the van Manen (1990) research process. Reflecting on Tim’s journey,
the love he had and the sacrifices he made for his children caused me to wonder what his feelings and thoughts were when he knew he was dying, knowing he was leaving them behind.

**A Father’s Love Story**

Tim’s imminent death, I am almost certain stirred an array of emotions between him and his children. His motivation and dedication towards them were so strong that I knew he would leave them with good memories and lots of love to cherish. I am also almost certain his children will continue to make him proud knowing he is there in spirit.

Tim, a husband and a father of two underage children was also a fighter. He was fighting a tough battle for his life against cancer. He was diagnosed with multiple myeloma, an incurable hematological malignancy. Once a diagnosis is made, a patient may enter remission but it is only a matter of time before the disease returns and the patient relapses. In Tim’s fight to live longer for his children, he made many sacrifices that eventually led him down an agonizing path. His cancer treatments and the associated side effects made him very ill but he never complained and adamantly continued with the prescribed protocol. His family, especially his children were his main priority and this was the price he was willing to pay to stay alive longer for them. He made this very clear to me the day he stated he will do whatever it takes to stay alive for them. Throughout the time that I had known Tim, he continuously talked about his children and their future. He hoped to be alive for their graduations, weddings and other important milestones.

Tim’s children were beautiful and their love and concern for their father was palpable. They were very involved in his care and he always spoke fondly of them. The love between them was evident especially during this difficult time and the thought of
leaving his children behind was more than he wanted to bear. Tim hoped that his cancer would go into remission. He centered in on the fact that being in remission would permit him extra time to spend with his children. Given more time on this earth, he would be able to demonstrate further how much he loves them and how grateful he is for the beautiful moments they share together. Tim never missed his treatments and on this one particular day, when he came into the clinic, it was the worse I had ever seen him. His teeth were clenched and his eyes were squeezed shut as he attempted to find a comfortable position on the chair. The agony on his face told me everything I didn’t want to know, and I knew at this moment his condition had taken a turn for the worse. His prognosis was poor and despite his condition, he insisted on receiving his chemotherapy. It would be the last time I ever saw Tim.

Several months later I received news that Tim died. My heart sank. Receiving word of Tim’s death touched my inner being. I thought of his journey and what his last days must have been like. In the face of death everything falls away, leaving that which is important (Jobs, 2005). Tim’s children were the most important thing to him and in wanting to stay alive longer to be with them looked past his physical condition and sacrificed comfort. In doing so, he displayed an incredible amount of strength and hope.

Vision sometimes arises from confusion (Bateson, 1989) and through the confusion of this loving father’s death, he had a vision of love. This was his legacy. He left a legacy of love behind for his children, a legacy that they will never forget each time they remember their father. And though, maybe Tim’s last days were full of suffering, I am sure he found some comfort in the love he shared and felt among his family. Through Tim’s dying process, I hoped every moment spent together was not wasted because no
one knew when he would take his final breath. And like the poem by Gabriel Garcia Marquez, I hope Tim was able to love and say farewell to his children during his final moments.

**Aim of the Study**

The main aim of this study is to describe and understand the lived experience of fathers with advanced cancer. From a pragmatic point of view, what in the experience contributes to the phenomenon of dying in a father with advanced cancer from a father’s perspective with underage children. Results from this qualitative study may provide new knowledge and insight for nurses to gain a better and deeper understanding of how to respond to and support fathers with advanced cancer as they confront the reality of their mortality as they live with a terminal illness. It could potentially facilitate communication between the family regarding topics such as advanced directives and policy development and education among staff members.

The second aim of this study will be to enhance and contribute to the discipline of nursing as a theory-based practice. In my attempt to accomplish this, a qualitative phenomenological design will be utilized as qualitative research methods do not borrow theory from other fields, rather theory springs from the observation of, and participation of an actual phenomenon (Munhall, 2007). Through the identification and comparison of the similarities from the fathers’ responses, the themes and essence that emerge could provide grounds for new theory development. In exploring the phenomenon of dying in fathers with advanced cancer, I hope to contribute to the nursing discipline through theory building.
The research question that will guide this study is “What is the meaning and the essence that comprise the experience of fathers with advanced cancer when death is imminent?” In achieving this aim, van Manen’s (1990) descriptive phenomenological method will be employed to explore this phenomenon. Exploring the phenomenon of fathers with advanced cancer when death is imminent, understanding their experiences and describing the essence thereof will be the outcomes of this dissertation.

The Phenomenon of Interest

The phenomenon of interest is the lived experience of fathers with advanced cancer when death is imminent. In a report by Cook, McGlynn, Devesa, Freedman & Anderson (2011) that looked at the National Cancer Institute’s (NCI) Surveillance, Epidemiology and End Results (SEER) database, compared information on survival and death rates for 36 different types of cancers and found that men in the United States are much more likely to develop and die from it than women. Cancer is a life-threatening illness that confronts and forces patients to see death as a reality and not just a possibility. One may try to rationalize this threat and perceive the disease as curable but as one’s physical condition deteriorates, these changes are irreversible and death approaches (Yang, Staps & Hijmans, 2010).

Dying is inevitable, it is possibly the one thing we can be sure of in this life and when it comes to cancer, men are more likely to die from the disease than women. Therefore any avenue to explore this phenomenon in fathers is important. This study’s focus on being a father with advanced cancer takes on added importance since a father’s presence in a child’s life goes beyond that of breadwinner and disciplinarian to that of
nurturer and friend. The presence of a father in a child’s life is essential and cannot be understated and will be discussed in chapter two.

Dying can be a feared or welcomed part of ones existence. Someone who is dying may hope that death is still a distant reality but for others who are suffering immensely and have accepted that to live is hopeless may welcome death as a way to end this chapter in their life (Glaser & Strauss, 1965). Death is a characteristic feature and a recurring part of human existence and people of every society and background must find ways to deal with it (Glaser & Strauss, 1965). It is a universal experience and destination we all share and no one has ever escaped it or ever will (Jobs, 2005). But how does a father prepare for a premature death when facing an advanced cancer diagnosis? What thoughts circulate his mind? What would his priorities be if he only had months to live?

Sociologists Glaser and Strauss (1965) in their monumental study, *Awareness of Dying*, researched the organization of dying in hospitals in the San Francisco Bay area. Their research focused on how modern western societies managed and communicated awareness about death. Four ‘*awareness contexts*’ were identified and their definitions are discussed as followed. ‘*Closed awareness*’ entailed that staff members kept patients ignorant of their impending death; ‘*suspicion awareness*’ is where patients were suspicious of their impending death and attempted to have the staff as well as family members confirm this suspicion; ‘*mutual pretense*’ describes where all parties were aware of the patient’s impending death but failed to acknowledge it and pretended everything was normal and finally, ‘*open awareness*’ where all parties were aware of the patient’s impending death, acknowledged it and were able to talk openly about it (Glaser & Strauss, 1965). This research will explore this phenomenon of interest in a specific
population of fathers with advanced cancer who are in open awareness of their prognosis and imminent dying status since there is no hope for a cure.

**Justification for the Study**

This study seeks to describe and understand the lived experience of fathers with advanced cancer. As the researcher, I am committed to this phenomenon in this population and strongly believe that something worthwhile and beneficial to nursing will result from it. Dying is inevitable, as a society we need present and committed fathers and cancer is a life-threatening disease that affects and claims the lives of many men every year. A review of the literature revealed that there is a paucity of research that has been done on parental cancer and even less has focused on fathers with cancer (Elmberger, Bolund & Lutzen, 2002; Helseth & Ulfsaet, 2005; Sheehan & Draucker, 2010). Therefore, understanding this phenomenon in this patient population is important. Exploring their fears, hopes and concerns for their children’s future, their current physical, psychological and spiritual condition as well as how they are coping is equally important. Fathers are important to a family unit and to society in general and describing and understanding this process is important to nursing and all that are involved in their care. I see this topic and study as pivotal and worth exploring.

According to SEER (2012), an estimated half a million men and women will die from cancer annually. This directly impacts and will involve nurses since they usually provide the majority of bedside care for patients, especially at the end-of-life. Through understanding the lived experiences of these fathers, nurses may become aware of what is important to these men at this critical time and be able to identify special needs, provide support and gender-specific necessary care. Nurses may also find ways to promote the
development of cognitive and emotional coping mechanisms specific for this population. As an oncology nurse, I have learned that throughout life there are opportunities for experiencing and managing a variety of roles and stressors and for this patient population, nurses should be aware of how being a father of underage children is a different phenomenon from that of a father with adult children. Examining the phenomenon from this perspective may enable the nurse to provide therapeutic interventions that may help in successfully managing the levels of stress these patients may endure (Roy, 2009). Based on this premise, I can say that this research may facilitate communication and interactions between the staff, the fathers and amongst their families.

**Relevance to Nursing**

Dying is a phenomenon and many social and psychological issues involved in this process may surface if the individual is aware that he or she is dying (Glaser & Strauss, 1965). This phenomenon becomes more important when looking at fathers and fatherhood. Receiving a cancer diagnosis elicits many emotional and psychological stressors and according to Hoyt (2009), there is a paucity of research on the emotional experience of men with cancer. Since this area of research is limited, describing and understanding this phenomenon in fathers adds to its importance as it may explore the emotional aspects that surround fatherhood or being a father with advanced cancer. As the disease progresses, and a father becomes more aware that he is dying, describing and understanding such emotions and concerns are important as it can guide gender-specific and patient-centered nursing care.

Since nursing is an art and a science, it is the nurse’s responsibility to assist, support and provide care to these fathers and their families and as well as assisting them
to address their concerns that surrounds the dying process and death (Kirshbaum, 2008). Results from this research may provide the nurse with a deeper understanding on how to provide such support and improve nursing care within this patient population. It may also enhance the nurse’s ability to feel comfortable and competent in educating, managing and supporting him and his family as they deal and cope with their current condition. In understanding this experience and the emotional aspects, a phenomenological qualitative research method is appropriate because it can explore areas of human behaviors or experiences that cannot be quantified (Roshan & Deeptee, 2009).

Understanding the constructs surrounding death and the dying process, such as one’s religious and cultural beliefs as well as their general impression of the experience is an important area in nursing. The dying process is dynamic and by describing and understanding the experiences of fathers with advanced cancer, the nurse may be able to understand their emotional behaviors, make tentative judgments and implement holistic nursing care and interventions that will provide satisfaction and support to the father and his family at this critical time of their existence (Roy, 2009).

Understanding how fathers perceive death and the dying process may shed light on an important area of nursing and raise public awareness about the matter. Results from this phenomenological study can promote changes in practice, increase nursing’s capacity for care and compassion and increase our consciousness about what was unknown or otherwise erroneous (Munhall, 2007). In understanding the lived experience of these fathers, other health care professionals may be better informed and patient education may be promoted. Through awareness, it is the goal of this research that knowledge and education among nurses will be enhanced as insights from this human experience is
described and understood and implications for support and awareness for palliative and
end-of-life services will be increased

**Phenomenon Discussed Within Specific Context**

The phenomenon under study is the lived experience of a father with advanced
cancer. The context for this study is a father whose main goal is to stay alive for his
children despite knowing that there is no cure and death is imminent. In this context, it is
not the phenomenon of fathering a child that is important but rather the father’s presence
and love that is necessary in caring for and raising these children as well as the legacy he
is building and will leave for them.

A life-threatening diagnosis such as cancer poses a major threat to the whole
human being (Nobis, Sanden & Elofsson, 2007) and profoundly affects the lives of the
other family members. In many instances cancer is looked upon as a death sentence
(Ferrell, Grant, Funk, Otis-Green & Garcia, 1998) and maintaining a stable family life is
extremely difficult when the trauma of such a life-threatening illness threatens one of the
parents who are expected to act as the anchor that nurtures and provides emotional
security for their children (Elmberger, Bolund & Lutzen, 2000).

**Fathers with Cancer**

The majority of cancer research has focused on women or mothers and not much
has focused on men as fathers or from a father’s perspective (Elmberger et al. 2002;
Helseth & Ulfsaet, 2005). It is needless to say that with such a life-threatening diagnosis,
the parent and their family are faced with many challenges (Sheehan & Draucker, 2011)
and research from a father’s perspective is also important.
The death of a young father is a major psychological event and may be the greatest tragedy a school-aged child may ever have to deal with (Parry & Thronwall, 1992). As compared to a sudden death such as in a car accident, fathers diagnosed with cancer usually have months or even years before they die. This grace period allows them time to prepare to die and they may use a variety of strategies. Fathers usually secure whatever financial benefits they have for their remaining families as well as leave remembrances such as video tapes and letters especially if their children are very young (Elmberger et al. 2002; Sheehan & Draucker, 2010). Adolescents spoke of their sick parent missing out on their proms, graduations, wedding and being able to spend time with their grandchildren after dying from cancer (Sheehan & Draucker, 2010).

**Fatherhood and A Father’s Presence**

Becoming a father is not merely defined by having a child or children. It is a constant presence, support and unconditional love that’s required by and deserving of his children. Ideally, the benefits of a father’s involvement in his child’s life, go beyond that of a financial provider to that of developing an emotionally stable psyche. For a child to develop into a healthy adult, empathetic responses from parents are necessary. An empathetic father is more likely to understand the inner emotional life of his child as well as helping the child to understand himself or herself. Not only does this promote self-esteem but it also places the father as the parent the child seeks comfort, nurturing and reassurance from (Dick, 2011).

There is evidence that clearly demonstrates the importance of fathers and their positive paternal involvement to the development of health and well-being of their children (Wilson & Prior, 2011). Positive paternal behaviors play an important role in
children’s adjustment over time. A lack of positive paternal parenting is related to a decrease in emotional security in children which leads to the development of externalizing and internalizing problems (Schacht et al. 2009). Adolescents’ perceptions of paternal support and closeness are positively correlated to their life satisfaction and well being (Young, Miller, Norton & Hill, 1995).

A father’s nurturance and authority is highly related to self-esteem (Amato, 1994; Buri, 1989). Paternal warmth promoted social competence and academic performance (Chen, Liu & Li, 2000). Women with binge eating disorder viewed their fathers as lacking in warmth and acceptance, being aggressive, neglectful and primarily rejecting them. Obese women with binge eating disorders perceived their fathers as rejecting (Dominy, Johnson & Koch, 2000). Children who identified a supportive father figure in their lives had higher cognitive scores, better perceived competence, fewer depressive symptoms and social acceptance as compared to children who did not identify a supportive father figure (Dubowitz, Black, Cox, Kerr, Litrownik, Radhakrishna et al. 2001). Positive father involvement and closeness yielded happiness, life-satisfaction and low psychological distress (Amato, 1994). A father’s positive involvement in his child’s life can have a positive impact on their development and marital relationship (Cowan, Cowan, Pruett & Pruett, 2006).

A father’s psychological absence has been shown to be a factor in increased sexual activity for girls (Fleck, Fuller, Malin & Miller, 1980). Girls with low father acceptance reported more petting and frequent sexual involvement as compared to girls with high father acceptance. A father’s psychological absence also correlated with increased anxiety as a personality trait and in dating situations (Fleck et al. 1980). Father-
child conflict was positively associated with adolescent depressive symptoms (Cole & McPherson, 1993). For children with attention deficit hyperactivity disorder (ADHD), a resident father is a buffer that is associated with the child having fewer symptoms (Sulak, Barnard-Brak & Frederick, 2012). Children without a resident father are reported to be less healthy, more likely to have ADHD, receive lower grades or repeat a grade, to be suspended or expelled as well as less likely to enjoy school as compared to children with resident fathers (DeBell, 2008).

The real or perceived absence of a father results in paternal deprivation. This is defined as the lack of a psychological experience from a meaningful father-child relationship (Dick, 2011). Fathers are central to the unconscious emotional development of our identity and their emotional or physical absence is often a major reason for adults to seek psychotherapy (Minsky, 2000). A father’s presence may affect his children’s development at all stages from infancy through young adulthood (Rohner & Veneziano, 2001). A father’s presence in a child’s life should not be understated as the literature shows a child’s psychological well-being and health depends on it. A father’s presence or love as discussed above is a sole significant predictor of specific outcomes.

**Assumptions and Biases**

My assumptions and biases stem from my experience as an oncology nurse. This chapter began with a true story of a father who focused was on living and loving though he was dying. Though Tim was not the first father I have cared for that has died, his story showed that dying is a stressful and worrisome experience to fathers. Saying goodbye to your children and hoping they will be taken care of financially and emotionally is not an easy task. However I find that in times of crisis, families bond together and value
whatever time they have left. I assume that the fathers I interview will be honest and forthright in sharing their stories by answering the questions during the interview process and that this research yields something of value and importance to the literature through understanding the experience of these fathers. It is the hope of this researcher, that through the interview process, there will be therapeutic value to the fathers as they talk of living with cancer, dying and leaving their young children behind.

**Summary**

This chapter began with a farewell letter written by Gabriel Garcia Marquez that speaks of saying goodbye to loved ones which may be a common theme of fathers with cancer such as Tim. This chapter discussed the aim, the phenomenon of interest, the phenomenon within context, the justification for the study and its relevance to nursing. As shown, the literature indicates a paucity of research on dying fathers with cancer and therefore confirms a gap. This enforces a need to conduct research in this area.

This chapter also reviewed the literature on the importance of a father’s presence. It revealed that there are many negative outcomes for a child when a positive father’s presence is absent. A positive father’s presence cannot be understated and it is imperative for a child’s stable emotional and physical development. This chapter concluded with the researcher’s biases and assumptions being revealed. The evolution of the study from a historical, experiential and conceptual perspective will be discussed in the next chapter.
CHAPTER II: EVOLUTION OF THE STUDY

Introduction

The literature is replete with research on mothers with cancer but falls short on research of fathers with cancer, confirming a paucity of research on this topic. Fatherhood, in general has also been historically understudied (Barclay & Lupton, 1999; Doherty, Erickson & LaRossa, 2006; Phares, Fields, Kamboukos & Lopez, 2005; Schacht, Cummings & Davies, 2009; Wilson & Prior, 2011). Since fathers are vital members in society and in their family’s lives, since they provide care and support to their children and family members (Rich & Ro, 2002), it seems only logical to understand how an advanced cancer diagnosis can affect a father’s outlook on fatherhood, death and dying and how the ramifications thereof may affect him, his children and his family.

This chapter includes a review of the literature that is relevant to the historical context and evolution of fatherhood. The researcher’s experiential context and Roy Adaptation Model as a conceptual framework is discussed.

Historical context

Historically, the mother was generally considered the dominant figure and being in a child’s care and development (Kagan, 1978; Premberg, Hellstrom & Berg, 2008). Consequently, much of the research within a familial context has focused on motherhood. In contrast, prior to the 1960s and 1970s, fathers were viewed as unimportant to a child’s development (Cabrera, Tamis-LeMonda, Bradley, Hofferth & Lamb, 2000) as they were traditionally seen as the breadwinner, disciplinarian, moral preceptor and educator (Atkinson & Blackwelder, 1993; Premberg et al. 2008; Wall & Arnold, 2007). As a result, the father’s role was seen as secondary and unimportant when compared to the
mother’s role. This was due to the father’s absent nurturing role in the child’s development and as a result, fathers have not historically been the focus of research.

Since then, fast forward to the fathers of modern day society, from the 1980s and beyond, fathers have increasingly taken on more of a nurturing role, developed closer emotional relationships with their children and also share in the joys and work of care-giving with their partners as compared to fathers from the 1950s to the 1970s (Maurer & Pleck, 2006; Wall & Arnold, 2007). Fathers who view the nurturing role highly central to their sense of self have been found to engage in significantly more interaction and take on more responsibility for their children (Rane & McBride, 2000).

In today’s modern western societies, the role and definition of men as fathers has evolved (Dick, 2011; Maurer & Pleck, 2006). Their role will continue to evolve and change with time as fatherhood is greatly influenced by several factors, many of which may be derived from a father’s internal motivations as well as his lived experiences (Dick, 2011). Fathering behaviors are being redefined and negotiated as men balance their external demands of work with their internal responsibilities of how they want to be as fathers (Olmstead, Futris & Pasley, 2009). Evidence suggests that the men in modern societies want to be more involved in raising their children than their fathers were with them (Henwood & Procter, 2003; Strauss & Goldberg, 1999; Wada & Beagan, 2006).

Research shows that many fathers in today’s society did not have a good role model when they were young as their fathers were more involved in a breadwinning role than that of a care-taking or nurturing role (Barclay & Lupton, 1999; Hamilton & Jonge, 2010; Henwood and Procter, 2003; Masciadrelli, Pleck & Stueve, 2006). Some men described their fathers as emotionally distant (abused or abandoned) and they did not
want to repeat this with their own children (Summers, Boller, Schiffman & Raikes, 2006). Henwood and Procter (2003) found that modern fathers saw their fathers as a disciplinarian and breadwinner and did not want to replicate that with their children. This latter generation of fathers found joy in taking responsibility for and caring for their child or children and the new way their family life had changed from that of being solely a breadwinner.

Being a father has been viewed as socially constructed, distinctive to a historical era and culturally unique (Dick, 2011). It is perceived by men as multi-dimensional and goes beyond the responsibility of simply being a financial provider (Clarke, O’Brien, Day, Godwin, Connolly, Hemmings, et al, 2005; Maurer, Pleck & Rane, 2001; Summers et al. 2006). A man’s view of himself as a father is complex and integrative (Olmstead et al. 2009) and incorporates many responsibilities that are necessary for a child’s healthy development. The literature is saturated with research on such responsibilities. They include being a teacher, a provider, disciplinarian, caretaker, supporter, co-parent, nurturer, role-model (Barclay & Lupton, 1999; Olmstead et al. 2009; Paschal, Lewis-Moss & Hsiao, 2011; Rane & McBride, 2000; Summers, Raikes, Butler, Spicer, Pan, Shaw et al. 1999; Summers et al. 2006; Tamis-LeMonda, 2004).

**Experiential Context**

As a young nurse, I began working in an outpatient oncology clinic in a large Metropolitan hospital in New York City in 2003. I’ve had many people ask me, “Why work with cancer patients? It is so depressing.” My response to them was why not care for a person who is fighting for their life against such a horrible disease? I’ve always seen myself as a caring and cheerful person as well as one to look at the glass as being half-
full instead of half-empty. I felt that my presence could bring a smile to someone’s face and that my compassion could heal a broken spirit. I believed that being part of a team that can extend someone’s life to see another birthday or celebrate another milestone was a reward in itself. I quickly fell in love with my new job as I enjoyed the personal interaction with my patients and their families as well as the level of clinical expertise that was required to care for these complexly ill patients. There was a mutual respect and affection that developed between my patients and I. Seeing them do well and respond to their treatment gave me a sense of fulfillment, accomplishment and pride that I was doing something I loved and for the betterment of humanity. I had found my calling and my true passion in caring for people with cancer.

As a young nurse, I quickly learned that not all cancer patients end up with a ‘happily-ever-after’ ending. Terminal cancer usually has a negative stigma attached and for almost 13 years I have seen the devastating effects it can inflict upon an individual and their family. Given the magnitude of hearing the words “you have cancer,” the stress and fear that is placed on these individuals is unfathomable. Then the real fight begins, the fight for time on this earth and the fight for one’s life. Cancer and its treatment are a tough ordeal. It includes frequent clinic visits, receiving harsh treatment protocols and numerous side effects. I’ve seen it take a toll on many patients and their loved ones. However, many patients endure such harsh conditions for months or years at a time because they hope for a cure or that their cancer will go into remission. While some patients have positive outcomes, there are many with negative and undesired ones. Many times the cancer will metastasize or simply stop responding to the treatment and when all treatment options have been exhausted, a patient is often left feeling even more hopeless
and helpless that before. At this point, what is a patient to do? Do they just wait to die? 
When my patients reach this stage, I also feel helpless. As an oncology nurse, you know
the fight ahead is going to be a tough one. You help as much as you can but you also
know your resources to slow the dying process are limited.

Cancer is such an unpredictable disease. One never knows the path it will take.
Though recent medical breakthroughs have been able to prolong life and increase cancer
survival rates there is still no cure. Regardless of whether one survives or not, dealing
with cancer remains a taxing, stressful and traumatic experience for all involved. In my
personal experience, I have seen many patients succumb to cancer and eventually die.

Regardless of age or diagnosis, I have found that women tend to be more open
about their feelings and concerns. Many of my female patients have never hesitated to
express their inner thoughts and openly show emotions in comparison to my male
patients. My male patients often times try to remain stoic, to emit a strong and silent
persona but not Tim. He was not afraid or ashamed to express his feelings and concerns
about his diagnosis, prognosis and concerns for the future. Tim knew that he would
eventually die because currently there is no cure for multiple myeloma but he did not
want to leave his underage children behind. He was doing everything in his power to stay
alive longer for them. It saddened him to that he would soon likely leave them and he was
burdened and concerned for their future. He knew that if he could go into remission he
would stay alive longer and be able to provide and care for their every need. Tim’s love
and concern for his children coupled with his openness to share his emotions was rare
and it affected my way and thought processes in caring for fathers.
As a daughter, I am grateful that my own father is alive and healthy. If I had lost my father to cancer as a young child my experience would have been shaped in a different way that may have influenced this research. Not only would it have affected me emotionally but as a source of preconception, and as a medium to introduce bias to this study. I have however attempted to place myself in such a situation as I see these fathers struggling to live as well as their loved ones hoping for one more day to be together despite knowing that they are or will soon die from such a futile disease.

In my eyes, a father that is prematurely dying from cancer is a tremendous loss to a family and I’ve realize that support is necessary as they go through this process. Since being affected by Tim, it has helped me to identify the need and importance for this study. There is work to do in supporting and assisting fathers through their dying process and I believe the first step lies in understanding what the experience means to them.

**Conceptual Context**

The Roy Adaptation Model (RAM) describes a person as a holistic adaptive system and seeks to understand how they adapt to various life situations (Roy & Andrews, 1999; Roy, 2009). The RAM as a conceptual model may be applicable to the findings of this study. The RAM sees the individual, such as a father with cancer as an open system that is in constant interaction with his environment. With this constant interaction, the human system receives input known as stimuli that elicits a response. Stimuli, such as the dying process, can induce an incredible amount stress that an individual must find ways to cope and maintain their integrity.

The RAM has four adaptive modes in which coping processes can be observed. These modes are the physiologic mode, the self-concept mode, the role function mode
and the interdependence mode. A father with cancer where death is imminent may have all four modes affected and therefore adaption is required to maintain function and equilibrium within the human system.

The physiologic mode includes the physical and chemical processes that are involved in the daily function and activities of living organisms (Roy, 2009). There are five basic needs specific to this mode and they include oxygenation, nutrition, elimination, activity and rest and protection. A father with cancer may have many of these needs compromised. As the cancer metastasizes and takes over the body, the body’s defenses become weaker and succumb to its negative effects. As a result death of the organism may approach. It is the goal of adaptation to maintain physiologic integrity whereby one maintains physiologic wholeness by achieving adaptation to changes in the physiological needs (Roy, 2009).

The self-concept mode focuses on the personal aspects of the human system. One’s feelings and beliefs about oneself is derived from one’s internal perceptions and the perceptions of others’ reactions (Roy, 2009). The main need is to maintain psychic and spiritual integrity so that one can exist with a sense of unity, meaning and purposefulness within oneself (Hanna & Roy, 2001). A father with cancer may have his self-concept mode compromised. Knowing that death is imminent, his role as a father may increase or decrease.

The role function mode encompasses the roles that an individual occupies in society (Roy, 2009). For men, those roles include being a good father. However, the role of a father may change or be compromised as he deals with a cancer diagnosis and begins to approach death. His role of provider may decrease but the role of giving love may
increase. The basic need is social integrity. This is the need to know who he is in relation to others so that he can act appropriately (Roy, 2009).

The interdependence mode focuses on close relationships between individuals and the ability to give and share love, respect, values, nurturing, knowledge, skills, commitment, material possessions, time and talents (Roy, 2009). It is a sense of feeling valued and supported by others. This mode may be strengthened when a father is dying. His family could be a strong support system where he receives love and support as well as giving love and support to them. The basic need is to maintain relational integrity and thereby feel secure in nurturing relationships (Roy, 2009).

When a human system’s equilibrium is challenged, the goal of nursing according to the RAM is to enhance life processes to promote adaptation in the four adaptive modes (Roy, 2009). A father with cancer where death is imminent may be faced with many stressors that he must learn to cope with. As this study evolves it will be interesting to see if the RAM fits appropriately with the themes that emerge.

Summary

This chapter explored the history and evolution of fatherhood. The researcher’s experiential context of caring for cancer patients as well as dying fathers with cancer was discussed as well as the conceptual framework of the Roy adaptation model as a framework that can be applied to the findings of this study. The next chapter will discuss the methodology that is known as phenomenology.
CHAPTER III: METHODOLOGY

The Phenomenological Method

The purpose of this study is to describe and understand the lived experience of fathers with advanced cancer when death is imminent. In exploring the experience of these fathers, a qualitative phenomenological approach is appropriate as it allows the researcher to explore how people experience their daily lives. Phenomenology has been defined as a systematic attempt to uncover and describe the meaning in one’s everyday existence, in their lifeworld. Its aim is to understand the lived experience (van Manen, 1990) or the essential structure of the lived world of conscious experience (Husserl, 1970). It is the study of essences (Merleau-Ponty, 1945/1962). An essence being the most essential meaning of an experience, or the true being of a thing (van Manen, 1990).

Phenomenology asks for the very nature of a phenomenon, for that which makes a thing what it is and without which, it could not be what it is (Husserl, 1970; Merleau-Ponty, 1945/1962).

Phenomenology is an approach to doing philosophy (Husserl, 1970) and has been used in nursing as such (Munhall, 2007). A phenomenological approach is of benefit to nursing because as a discipline we are concerned with understanding the human being in a holistic manner. In conducting phenomenological research, the nurse is able to understand the person’s experience and be with them in an authentic manner. As these fathers share their experience, the phenomenological method seeks to uncover the essence of their experience. This allows the nurse to understand what being a father is like for them. In this chapter the history and evolution of phenomenology is discussed,
specifically the philosophical viewpoint of Maurice Merleau-Ponty (1945/1962) and the phenomenological method of Max van Manen (1990) that will guide this study.

**Edmund Husserl (1859-1938)**

Husserl is considered to be the founder of phenomenology. A transcendental phenomenologist, his main focus was on the pure description of the lived experience (Annells, 1996). His concept of the lifeworld refers to the individual’s direct experience to the everyday world in which they live (van Manen, 1990). Husserl’s phenomenology came to mean the description of phenomena as it is lived and constituted and experienced through consciousness (Husserl, 1970). Through phenomenological reduction, Husserl (1931) asserted the elimination of all preconceived notions whereby a subject may come to know an essence directly. This is known as bracketing. Bracketing purifies the consciousness that he sees as intentional and necessary to achieve credibility and rigor and reduce bias. Intentionality refers to the internal experience and an inseparable connectedness of being conscious to the world (van Manen, 1990) and therefore essences is dependant on consciousness (Husserl, 1931).

**Maurice Merleau-Ponty (1908-1961)**

Merleau-Ponty (1945/1962) was an existential phenomenologist. He saw the existence of people in a pre-given world whereby they return to the very thing, in search of essences and seeing this as part of the lived and experienced world that has not been reflected upon. His phenomenology focused on the importance of perception and the individual’s situation in the world through experience (Merleau-Ponty, 1945/1962). Like
Husserl, his emphasis was on phenomenological description rather than interpretation and he advocated for phenomenological reduction as a way to reach an original awareness.

Merleau-Ponty (1945/1962) philosophy provides the framework for this study. Several of his themes are critical to the philosophical foundation of this study and they include the lived experience, embodiment and primacy of perception. Among these three is also the concept of consciousness which he defined as a sensory awareness and response to the environment (Merleau-Ponty, 1945/1962). He saw consciousness as the state in which one relates to the world and allows for description of one’s lived experiences with the world. He encouraged people to see the world as new, to rediscover it as if they were experiencing it for the very first time. The second theme is embodiment. This entails that through our bodies we have access to the world and it is through perception that we know both our interior and exterior worlds. The body is our anchor to the world (Merleau-Ponty, 1945/1962) and though the conditions of the world may limit the body, it does not determine it. People are in charge of determining their bodies through their own choices. Embodiment gives meaning to the space around itself. It is through consciousness and embodiment we are aware of being in the world and we gain access to the world. The third theme is primacy of perception and it proposes to rediscover the first experience. Merleau-Ponty (1945/1962) defined primacy of perception as the experience of perception that is our presence the moment when things, truths and values are constituted for us. He saw perception as the thing that forms and increases the awareness of the experience or reality that provides direct experience to the phenomena and the world.
Merleau-Ponty (1945/1962) believed that through one’s life experiences, an individual has the ability to find meaning in and understand life itself. His philosophy is a perfect fit for my study given that he views humans as experiencing the world through the body, which is the most appropriate philosophical underpinning for this qualitative nursing research. Through consciousness and embodiment these fathers are aware of their being, their lived experience and their perception in this world. Exploring this phenomenon through their specific human perception is the goal of this research.

Max van Manen

Max van Manen, a Canadian social scientist and educational philosopher, described phenomenology as the difference between a research methodology and a research method. He refers to research methodology as the philosophical framework, the fundamental assumptions and the characteristics of a qualitative approach and as a research method, he described it as the techniques and procedures utilized to conduct the research (van Manen, 1990).

van Manen’s (1990) phenomenological (existential-descriptive-hermeneutic) method is greatly influenced by Merleau-Ponty (existential), Husserl (descriptive) and Heidegger (interpretive) philosophies and consists of six research activities. Based on its recent development and the structure it provides for analyzing data, van Manen (1990) phenomenological method was selected for this study. The six research activities are mentioned here but their specific application to this study will be described in greater details in the next chapter. The research activities include:
1. Turning to a phenomenon which seriously interests us and commits us to the world.

2. Investigating experience as we live it rather than as we conceptualize it.

3. Reflecting on the essential themes which characterize the phenomenon.

4. Describing the phenomenon through the art of writing and rewriting.

5. Maintaining a strong and oriented pedagogical relation to the phenomenon.

6. Balancing the research context by considering parts and whole.

Summary

The primary goal of this research is to capture the essence of these fathers, through describing the phenomenon and gaining a deeper understanding of their experience (van Manen, 1990). Utilizing a phenomenological method will assist this researcher in attaining this goal. This chapter began with a description and rationale of the research design chosen for this study. It included the discussion of Husserl as the roots of phenomenology, the utilization of the philosophy of Merleau-Ponty and the six phenomenological research activities of van Manen. The next chapter focuses on the application of van Manen’s phenomenological research activities and the steps that will be taken to conduct the proposed research study.
CHAPTER IV: METHODOLOGY APPLIED

Introduction

The lived experience as described and discussed by Merleau-Ponty (1945/1962) will be the philosophical underpinning for this research, concurrently with the phenomenological research method derived from van Manen (1990). This chapter will discuss the application of the van Manen (1990) phenomenological method to this study. Specifically, it will discuss the steps that will guide the researcher in collecting and analyzing the data, to describe and understand the meaning and the essence that comprise the experience of fathers from advanced cancer.

van Manen’s Phenomenological Research Method

The first step in van Manen’s (1990) phenomenological method is “turning to a phenomenon which seriously interests us and commits us to the world.” This describes a phenomenon that I, the researcher is interested in and is committed too. van Manen (1990) sees it as a true task or a deep questioning of something that restores an original sense of what it means to be a thinker, researcher and a theorist. Since my interactions with Tim, a deep concern for the emotional care of fathers with advanced cancer as well as a desire to understand how they cope with their reality has resonated within me. This research speaks volumes as a testament of my commitment to this phenomenon. In my quest to bring about a better understanding of the experience of these fathers, I hope that nursing as a profession will also gain a better understanding of what is important in
caring for these men as they simultaneously fight to prolong their lives and make the most of the time they have left.

The second step “investigating experience as we live it rather than as we conceptualize it” means to be aware and be a part of the participants world. Phenomenological research aims at establishing a renewed contact with the original experience. This orients the researcher to stand in the fullness of life and in the midst of the participant’s world thereby actively exploring their lived experience in all its modalities and aspects (van Manen, 1990). Being an oncology nurse already makes me aware and places me as part of the participants’ world. As an oncology researcher, it is my aim to fully explore these fathers’ experiences. This research will be conducted through face-to-face interviews. As the researcher I plan to listen without bias and to be present to hear their lived experience (van Manen, 1990).

The third step is of “reflecting on the essential themes which characterize the phenomenon.” Phenomenological research makes a distinction between appearances and essences. The insight into the essences of a phenomenon involves a process of reflecting, appropriating, of clarifying and making explicit the structure of meaning of the lived experience (van Manen, 1990). The meaning of lived experiences is usually hidden or veiled (van Manen, 1990) therefore by transcribing verbatim the conversation of each participant, I plan to immerse myself in the data to reveal and unveil the themes and essence of these fathers. Reflecting and organizing the emerging themes can illuminate the essences of their experiences.
The fourth step of “describing the phenomenon through the art of writing and rewriting” deals with bringing something to speech along with the application of language and thoughtfulness (van Manen, 1990). Through interviewing these fathers and then dwelling in their words, I will be able to rewrite, re-think, re-reflect, and re-cognize (van Manen, 1990) the emerging themes thereby allowing the experience of the fathers to be seen.

“Maintaining a strong and oriented pedagogical relation to the phenomena” is the fifth theme. The purpose of this step is to establish and maintain a strong relationship with the phenomenon in order to avoid speculation, detours and narcissistic reflections (van Manen, 1990). My goal is to remain oriented to the research question, the phenomenon and the human experience. The idea is not to wander aimlessly or settle for wishy-washy speculations or superficialities and falsities (van Manen, 1990). During the interview process, I plan to ask open-ended questions to allow the participants to describe their experience but at the same time, remain focused on the phenomenon and sensitively draw the participants back to their experience should they diverge on different tangents. A commitment to the integrity of the study will be maintained.

The final step to van Manen’s (1990) research activities is “balancing the research context by considering parts and whole.” In searching for the “whatness” of the phenomenon, one may lose sight or get stuck in the end of phenomenological research (van Manen, 1990). If and when this occurs van Manen suggests stepping back at several points to look at the total, at the contextual givens and how each of these parts contribute
to the whole. At data analysis it is important to keep an open mind and to observe how the data flows and the themes emerge.

**Aim of the Study**

The aim of this study is to describe and understand the lived experience of fathers with advanced cancer where death is imminent. The participants will be asked to share their experience and what it means to them. The themes and essence that will be revealed from this research will provide insight for nursing to offer support as we understand what is important for these fathers at such a time in their lives.

**Sample**

A purposive sample for this qualitative research will be obtained. Purposeful sampling in qualitative research means that the researcher selects individuals who have experienced the same phenomenon and can therefore purposely inform the researcher in understanding the research problem (Creswell, 2007; Polit & Beck, 2004).

A purposeful sample of fathers with advanced cancer was recruited from a large hospital in New York City. Phenomenological research tends to necessitate a very small sample of participants. According to Creswell (1998) and Polit & Beck (2004), typically ten will suffice but this number is usually determined when data saturation is reached. Data saturation is defined as the point where sampling yields no new information and redundancy is achieved (Polit & Beck, 2004). At the point of data saturation and redundancies, data collection for this study was ceased.
The participants for this study were first-time fathers with an underage child or children that are eighteen years old or younger. The fathers were diagnosed with an advanced cancer or are at a stage for which there is no cure. They fluently spoke and understood the English language. All participants were cognitively stable, alert and oriented to time, place and person. Fathers with a primary cancer source or metastasis to the brain or have any cognitively impaired conditions such as dementia were excluded from this study.

**Setting**

The setting for this study took place in a quiet, private location that is convenient for each participant. Since in-depth interviews is the data collection tool for this study and the participants may be in a vulnerable state, a quiet and private space may allow them to feel more comfortable to share their experience.

**Gaining Access**

Institutional Review Board (IRB) was obtained from Lehman College, City University of New York (CUNY) and a large hospital in New York City where I am employed. Upon IRB approval from both institutions, the recruiting process began by contacting all oncologists, hematologists, nurse practitioners, physician assistants, registered nurses and social workers via email alerting them of the study and the inclusion criteria. Their assistance in the identification of participants was necessary to ensure a successful recruitment process. As potential participants were identified, the medical providers made the initial introduction to the study and if the potential
participants were interested or wanted to learn more, I met with them to give more
details.

**Protection of Human Subjects**

Terminally ill patients are considered a vulnerable population because they are
more vulnerable to coercion and present with more than a minimal risk. The IRB
approval was obtained from Lehman College, CUNY and a large hospital in New York
City. Upon the identification of the potential participants, each was screened to determine
if they met the inclusion criteria. Those that did, had the research purpose, the aim, goals,
advantages/benefits and disadvantages explained and clarified. The potential participants
were informed that participation is strictly voluntary and could withdraw from the study
at any time without being penalized. The participants were allowed 24 to 48 hours if
needed, to decide if they would like to participate. Once each participant were fully
knowledgeable, felt comfortable and expressed a desire to participate, a date, time and
place was scheduled to meet where the informed consent was signed and the first
interview was conducted.

According to Seidman (2006), as per the Nuremberg Code, an imperative ethical
principle of research with humans is that their participation is completely voluntary and
free of fraud, deceit, constraints or coercion. An informed consent should provide
sufficient knowledge about the study so that they can make a true informed decision on
whether they want to participate or not. Requirements for an informed consent should
include an invitation to participate, disclosure of information that is pertinent to the
research purpose, background and procedures as well as a participant’s voluntary
agreement to participate. A description of the risks, rights and possible benefits to the participants should also be included. Explanations of confidentiality, dissemination of results, considerations for children and the researcher contact information should also be included (Seidman, 2006).

Each participant was de-identified by assigning a pseudonym that maintained their anonymity. The interviews took place in a quiet and private setting where the participants felt safe and secure and where their privacy and confidentiality were protected. All participant data that included recordings, transcriptions, encryptions and other pertinent information was secured in a locked cabinet. A password was also assigned to the researcher’s computer.

Though these fathers with cancer comprise a vulnerable population, more than minimal risk may not be anticipated as they are aware of their status and live with their condition every day. However, in the case of speaking and reflecting on their condition and being reminded of their terminal illness and leaving their children, strong emotions and distress such as crying may arise. If distress occurs at any point during the interview, participants will have the option to stop the interview, speak to their mental health provider or religious leader. A list of local support groups was also available. It was established in the beginning that the researcher was not there to provide therapy but to conduct research (deMarrais & Tisdale, 2002). I, the researcher was also aware of my feelings on dying as the interviewing process may illicit strong emotions. Seeking psychological assistance may also be necessary.

Data Collection
As potential participants are identified, data collection began with the first meeting. They were screened to determine if they met the inclusion criteria. Once this was met and they agreed to participate, a date, time and location for the initial interview was set by each participant. At that time, informed consent was obtained, a demographic questionnaire was completed and then the first face-to face in-depth interview took place. Each interview may last for about 60 minutes but it is important to note that each interview time may differ. An in-depth interview is defined as a process whereby a researcher asks questions to participants and they respond with their thoughts, perspectives and narratives based on their lived experiences (deMarrais & Tisdale, 2002). Each interview was audio-taped by two tape recorders. One tape recorder was used as a back-up in the event of equipment failure.

At the heart of interviewing, research is an interest in the stories of others (Seidman, 2006). Each father was asked to share their experience of knowing they have an advanced cancer and what it means to them. Each interview started with a general lead question similar to “Tell me about your experience of being a father and having __________ cancer”. As the participants then began to share their experience, open-ended questions was asked that explored their experience and what it means to them. The interview process and questions were guided by the responses of each father. Exploration and clarification during the interview process was sought by asking questions such as “What does that mean?” or “Can you give me an example?” I was mindful and allowed each participant sufficient time to speak and limited interruptions. They were encouraged to speak until they felt there was nothing more to say on the topic. Each interview ended
by asking the participant if there was anything else they wanted to share. Participants were recruited until data saturation was achieved.

Revisiting the participants for a second interview if necessary, was done as suggested by van Manen (1990). He suggests going back to the interviewee to discuss the ongoing record of the interview transcript. In this study, each participant reviewed their transcript for accuracy and determined if the emerging themes reflected their experience as they told it. If there was a need for clarification or further questions, a second interview was scheduled accordingly to address these issues.

Data Analysis

The data was analyzed using van Manen’s (1990) phenomenological method. At the end of the interviews, when data saturation was reached, each interview was transcribed verbatim. I then dwelled in the raw data and text. Each interview was read line by line, several times seeking words and phrases that described the phenomenon being explored. These phrases were identified and placed into categories and were reviewed for emerging themes. These themes are the experiential structures that make up the experience (van Manen, 1990). Therefore it is within these essential themes that the essence of the fathers’ experience will emerge.

Reliability, Validity and Rigor

Husserl (1970) was interested in an ideal philosophy as a rigorous science. He believed that by using the method of *epoche* or bracketing which he defined as holding in abeyance one’s presumptions, then one can seek the roots or beginnings of knowledge in
the subjective processes of the thing itself. He saw this as a way to reduce bias and increase rigor. Merleau-Ponty (1945/1962) also advocated for bracketing as a way to see the world as new, as if they were experiencing it for the first time however, he stated that complete bracketing is not possible. van Manen (1990) did not embrace total bracketing. He thought that if we try to forget what we already know it may creep back into our awareness. As the researcher, my aim was to avoid bias and enable things to be seen as they emerged. As a result, I attempted to bracket as a way to remain in the unknowing and approached each participant and their experience as unique. I was present and listened to each participant, to learn and understand their stories, experiences and meanings (Thomas & Magilvy, 2011).

Rigor in qualitative research is achieved when the study is believable, accurate and useful to other people beyond the participants (Priest, 2002). Lincoln & Guba (1985) suggested criteria aimed at maintaining rigor through credibility, dependability, transferability and confirmability. Rigor is useful for establishing consistency of the study methods over time and provides accuracy in representation of the studied population (Thomas & Magilvy, 2011).

Seeking approval and clarification from each father for accuracy of their transcript and description of their experience is a way to maintain rigor and credibility. Should discrepancies arise, re-interviewing the participant may be necessary. Credibility, the faithful depiction that allows others to recognize the interpreted experiences of the participants in a study will be achieved through prolonged engagement (Lincoln & Guba, 1985). One should be able to identify and say this is an experience any other person could
have had. A good phenomenological study is one that someone can nod to (van Manen, 1990). Transcripts will also be read by one or more researchers or experts independently of each other in order to come to an agreement about the descriptors and themes that emerge. This is a way to maintain dependability and confirmability (Lincoln & Guba, 1985) as well as reliability (Cook, 2011). Re-interviewing also adds to the reliability in qualitative research. Transferability refers to being able to transfer research findings and methods or its applicability from one group to another (Lincoln & Guba, 1985).

The researcher must be reflective and maintain a sense of awareness and openness as the study unfolds and themes emerge. To prevent my own knowledge, past experiences and preconceptions from affecting the research, journaling as a way to keep personal feelings, biases and other insights under control may be beneficial (Thomas & Magilvy, 2011).

**Limitations**

A major limitation with qualitative research is that it is not generalizable to the general public as quantitative research is. This is due to the small sample. This, however is not to negate or minimize the benefits of qualitative research as qualitative research allows for a deeper and richer understanding of a phenomenon which can easily be missed with quantitative research (Thomas & Magilvy, 2011). Another limitation to this study is that some fathers may be resistant and withdraw from participating should they be overwhelmed with emotions and concern with their current situation. It will be reinforced that they can withdraw from this study at any time and a list of local support
groups will be provided. As the researcher I will remain sensitive and non-judgmental so as to gain their trust and maintain rapport through the interview process.

Summary

This chapter discussed in detail the six research activities of van Manen (1990) and its applicability to this study as well as the steps the researcher will take in recruiting and interviewing participants. The process for data collection, data analysis and steps to maintain patient confidentiality and rigor to the study were also discussed.
CHAPTER V: STUDY FINDINGS

Introduction

This study sought to describe and understand the phenomenon of the lived experience of fathers with advanced cancer when death is imminent. The participants were fathers of a child or children who are eighteen years old or younger, and diagnosed with cancer that is at a stage for which there is no possibility for a cure. A descriptive phenomenological approach as outlined by van Manen (1990) was used to analyze the data. This chapter explains the study recruitment process, the study participants and a description of each participant’s experiences, the methodology applied to the research process, narrative phrases that captured the meanings of each father’s experience, the emergent themes and study findings as well as the concluding interpretive statement.

Research Setting

The main research setting for this study took place at the cancer center, and hospital where I work and the participants receive care and treatment for cancer. However, two participants were interviewed elsewhere at a convenient location of their choice. A total of ten fathers were recruited for this study. Five were interviewed in private conference rooms in the outpatient setting, three were interviewed in the in-patient setting in the privacy of their hospital rooms, one father was interviewed in a park and one in the privacy of his home. Each setting allowed for privacy in a quiet space where each participant shared his story and experience.

Study Sample

The study sample consisted of ten participants. Of those, four were Caucasian, four were Hispanic, and two were African American. All participants indicated that they
were their children’s biological father. Two fathers had four children, two fathers had three, three had two children and three had one child. The children’s ages ranged from 8 months – 18 years of age and the father’s ages ranged from 30 – 60 years of age. Five of the participants were married and lived with their spouse and child or children, one was engaged and lived with his fiancé and children, one was separated but not divorced, one was divorced, and two fathers were never married and lived separately from their child or children. However, they were all present fathers and shared in the responsibility of caring for their children. Two fathers were working full time, one worked part-time, four were unemployed, one was retired, and two were on disability.

Each participant was screened to determine if they met the inclusion criteria. If this requirement was met, they were formally asked to participate. A pseudonym was assigned to each participant to remain anonymous and protect their privacy. A date and time was set to conduct each interview and the fathers were informed that they will need to sign an informed consent, completed a demographic questionnaire and receive a list of local support groups prior to the interview. They all verbalized understanding and agreed. Each interview began with a similar lead question of, “Tell me about your experience of being a father and having cancer.” All interviews were recorded via two tape-recorders, one was used as the original and one as a backup. All interviews were transcribed verbatim. The following sections will give further details and descriptions of each father’s recruitment process and experience.

The following table represents the demographic data of the fathers’ ages, diagnosis and their children’s ages.
<table>
<thead>
<tr>
<th>Father’s pseudonym</th>
<th>Father’s age</th>
<th>Father’s diagnosis</th>
<th>Children’s ages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sam</td>
<td>46 years</td>
<td>Multiple myeloma</td>
<td>12, 11, 4 &amp; 1 years</td>
</tr>
<tr>
<td>Joe</td>
<td>57 years</td>
<td>Stage IV pancreatic neuro-endocrine cancer</td>
<td>10 &amp; 8 years</td>
</tr>
<tr>
<td>Dean</td>
<td>52 years</td>
<td>Multiple myeloma</td>
<td>6 years &amp; 21 month old twins</td>
</tr>
<tr>
<td>Shawn</td>
<td>40 years</td>
<td>Acute myeloid leukemia</td>
<td>5 years</td>
</tr>
<tr>
<td>Jose</td>
<td>30 years</td>
<td>Stage IV renal cell carcinoma</td>
<td>16, 13 &amp; 3 years</td>
</tr>
<tr>
<td>Charlie</td>
<td>34 years</td>
<td>Stage IV urachal cancer</td>
<td>8 months</td>
</tr>
<tr>
<td>Dave</td>
<td>45 years</td>
<td>Stage IV pancreatic cancer</td>
<td>11 years</td>
</tr>
<tr>
<td>Rob</td>
<td>60 years</td>
<td>Multiple myeloma</td>
<td>10 &amp; 7 years</td>
</tr>
<tr>
<td>Antonio</td>
<td>47 years</td>
<td>Stage IV lung cancer</td>
<td>18 &amp; 11 years</td>
</tr>
<tr>
<td>Woody</td>
<td>38 years</td>
<td>Stage IV renal cell carcinoma</td>
<td>15, 12, 8 &amp; 6 years</td>
</tr>
</tbody>
</table>

Table 1: Demographic Data
Study Findings

This study sought to describe and understand the phenomenon of the lived experience of fathers with advanced cancer when death is imminent. Tape-recorded interviews were conducted as the data collection method and were analyzed to describe and understand the phenomenon being studied. The recruitment and interview processes were used to develop a relationship with the participants and build rapport, giving a first-hand account of the phenomenon under study. According to van Manen (1990), this is the second step of the research process. It allowed the fathers to establish a renewed contact with their experience and for myself, the researcher to actively explore their lived experience in all modalities and aspects. The interview process allowed me to investigate the experience as each participant experienced it (van Manen, 1990). Human experience is only possible because we have language. Talking about experiences rather than writing about them is easier because talking leads to a more genuine recollection and truth to the lived experience (van Manen, 1990). The following sections provide a more detailed look at each father to gain a better understanding of the circumstances they face as it relates to dealing with advanced cancer when death is imminent. These descriptive reports are meant to provide an imagery that yield clues and give insights into each father’s experience and apart from the actual dialogue such descriptions can provide an imagery of the participant and their personality.

The Recruiting Process and the Participants’ Experiences

The recruitment process began after I secured IRB approval from Lehman College and a large hospital in New York City where I am employed. A formal email was sent to my colleagues describing my study and asking for their assistance in identifying
male patients that may fit the inclusion criteria and would be receptive to learning more about the study.

**Sam:** After sending the initial email, a couple of weeks later, one of my colleagues told me about Sam. He is a 46-year-old Caucasian male, diagnosed with multiple myeloma and is the father of four young children, whose ages ranged from 1 – 12. One afternoon in August, I was introduced to Sam as he received his chemotherapy. I performed the initial screening and discussed the study protocol in private and greater detail. Sam stated he understood what the study entailed after I answered the few questions that he had, and he verbally agreed to participate. “This is my chance to give something back for the excellent care I have been receiving here,” he stated. At that time, we agreed to conduct the interview two weeks after his subsequent chemotherapy.

As scheduled, two weeks later, we met at the cancer center in a private reserved conference room. A “do not disturb, meeting in progress” sign was placed on the door. Sam appeared comfortable as we sat across each other at the conference room table. He is a tall, slender but muscular man and was wearing a gray polo shirt and jeans. The study was reviewed once more, he had no further questions or concerns and was consented. The interview began when I asked him to tell me what his “Experience has been like being the father of four young children and having multiple myeloma?” Sam was not reserved or shy in his response. He began telling his story from the beginning when he first received his cancer diagnosis. The following is a brief excerpt from his interview that gives description to his experience of as a father with an incurable cancer:

I kind of looked at them (his children) like, oh my god, I’m not going to see them when they’re old and that was a weird, hard feeling…it’s easy to not accept dying but understand that, oh it’s going to happen at some point anyway. I feel lucky that up until that point I’ve been able to have a family and enjoy my life.
The interview lasted approximately 40 minutes and was interrupted when Sam needed to use the restroom. When he returned, we closed the meeting. In closing, I asked Sam if there was anything else he would like to share with me regarding being a father with cancer and having young children or anything else that we did not cover during the interview. He responded by saying the major things we already discussed. We conversed for a few more minutes and the interview ended. I humbly thanked Sam for sharing his experience of with cancer with me. I asked what would be his preferred method for me to share the transcript with him. He opted for it to be sent via email as this would facilitate communication and be easier for him to provide feedback. We shook hands, I thanked him again, we both smiled and parted ways. After he received and reviewed the transcript he responded via email, “All looks great on the transcript.” There was no need for further clarification.

Later that day as I sat back and reflected on the interview, I remembered how composed he was. It surprised me that he did not get overly emotional or cried. His love and concern for his children and their future were evident. There were moments when I felt overwhelmed with the details and emotions he shared. I felt happy and accomplished that I did my first interview but so humbled that someone was willing to share such private and intimate details of such a life-altering and life-threatening disease.

**Joe:** A few days later, after my first interview, I met Joe. A brief review of his chart indicated he had two young children, ages 8 and 10 and fit the inclusion criteria for my study. He was 57-years old and was diagnosed with stage IV pancreatic neuro-endocrine cancer. I asked his oncologist’s permission to approach him, she agreed. I introduced myself to Joe as a nursing researcher, stating I am actively recruiting participants and
asked if he would like to hear more details, he said sure. I described the study to him, focusing on the need for this research, its benefits, risks and other pertinent information. I formally asked if he would like to participate and he said yes. We decided on a date that was convenient, which was later that same week.

Joe was a tall Caucasian man with gray hair that looked older than his age. He wore a blue polo shirt and jeans. We met at the cancer center in a private reserved conference room. A “do not disturb, meeting in progress” sign was placed on the door. He looked slightly uncomfortable and nervous as we sat across from each other at the conference room table but casual conversation made him feel more relaxed as he settled into the chair. The study was reviewed, he had no questions and he signed the informed consent. The interview begun when I asked him to tell me about his experiences as a “Father with metastatic cancer.” Below, is a small excerpt from his interview relating to his experience of being a father with cancer, “I just keep my emotions under check and stay alive you know, till they’ve grown up maybe a little. I’d hate to die before they’re before they’re 20 (years old) even.”

During the interview, Joe was a man of few words. He did however, talk about how emotional this experience has been for him and how he enjoys spending time with his children. Talking about his children made him smile several times during the interview. The interview lasted approximately 20 minutes and ended when I asked if there was anything else related to being a father with cancer that he wanted to share to which he responded “no.”

At the end of the interview, I thanked him for participating. He hoped his story will help my research and I said it most definitely will. I asked him how he would prefer
for me to send him the transcript. He opted for an email. Several weeks after he received the transcript he agreed with it and said that he is sure I will receive an “A.” There was no further need for clarification.

**Dean:** Several months went by before I met my third participant. My colleague informed me of Dean and gave me a brief background on his cancer and current condition. He was 52-years-old, diagnosed multiple myeloma and has three very young children, a 6-year-old son and 21-month old fraternal twins. She had given him a brief introduction to the study and he expressed interest in knowing more. He was being admitted to the hospital for a bone marrow transplant (BMT) and he agreed to be interviewed there. I asked her to give him my mobile number and requested his. He agreed. The next day, I called him stating that I will visit him in his hospital room to screen him, discuss my study in greater detail and to answer any questions or concerns he may have. He agreed. A couple of days later I visited him. He was screened, and I discussed my study. He had a few questions that I answered to his apparent satisfaction. We talked for a while longer and decided on a day to conduct the interview. He decided the very next day would be suitable.

As scheduled, the very next day in the evening, I went to interview Dean. He had already received his BMT and was on a strict schedule of various medications. Due to hospital protocol, I could not put a “do not disturb” sign on the door but his nurse was aware that we were conducting an interview and promised not to interrupt unless necessary. Dean was a short, bulky Caucasian man who looked like he hadn’t showered and shaved for a few days. His facial hair was gray and he was wearing a black t-shirt and sweatpants. He had a triple lumen venous catheter oddly placed to the right side of his neck that was connected to an intravenous (IV) pump that continuously infused his
medications. He looked quite uncomfortable as his head seemed permanently tilted to the left side. He was laying in bed and I sat adjacently to him while we conducted the interview. After he signed the informed consent, the interview began when I asked him to tell me “What your experience has been being a father diagnosed with multiple myeloma.” The following is a small excerpt of his interview that gives a description of his experience of being a parent with cancer:

Anytime someone tells you that you have a disease that’s going to end your life, it’s a very hard thing to accept. First of all, from my standpoint, I have young kids which makes it worse. I can’t afford not to be here you know, I don’t want my children to not have a dad, they’re so young. So if someone tells you something that can put an end number on your life on this planet, it’s not a nice thing at all.

The interview lasted about 40 minutes and ended with me asking him if there was anything else that he wanted to share about being a father, having kids or having multiple myeloma to which he said no. Dean was liberal and verbal in sharing his experience. He gave many details about how being a father with cancer has affected his life and changed his perspective on what’s important. I thanked him for being so open and transparent regarding his story. I asked Dean how he would like me to give him the transcript for his review. He also opted for it to be sent via email. We shook hands, I thanked him again, and I left. A few weeks after receiving the transcript, I received a text from Dean stating that I can “use it as it is.” Further clarification was not necessary.

Shawn: During August 2014, my nurse manager emailed me a list of male patients she knew were fathers and possibly met the inclusion criteria. Shawn was included in that list. A review of his chart revealed that he was 40 years old, was diagnosed with acute myeloid leukemia (AML), and had a five year old son. I then reached out to my colleague who cares for him asking her to do the initial introduction to the study and ask him if he
would like to learn more. I was told that he is intrigued by my research topic and would love to learn more. That same day, I approached him, introduced myself, and did the initial screening. After sharing the details of the study with him and his wife who was also present, he decided that he would love to participate but that he would not be able to do so in the next few weeks. Shawn’s AML was not responding to the traditional chemotherapies, and he was being admitted for an allogeneic BMT. He was very sick and fragile and wanted me to contact him within two to three weeks to assess how he was feeling and if he was able to be interviewed. I agreed and at that time we exchanged mobile numbers, I thanked him for his time and I left. Two weeks later I contacted Shawn but he did not respond. Another week went by and no response. I spoke with my colleague regarding his status, and she said he is doing well and should be discharged from the hospital soon. The following week, Shawn had a follow-up appointment with his oncologist at the cancer center. I remember feeling relieved that he was out of the hospital and doing well. I did not get a chance to speak with him that day but followed up with a phone call a few days later. He informed me that he was doing well, that the BMT worked, and he was in remission. In my profession, there is nothing better than hearing those words as you always want your patients to do well. He stated that he has another appointment coming up the following Monday and that we could follow up in person at that point. I agreed.

On the appointment date, I looked forward to seeing Shawn, but my colleague informed me that he came in with severe bone pain, that his laboratory work showed an elevated white blood cell count and that he was being re-admitted for relapse of his AML. My heart sunk. It was only ten days since he was discharged from the hospital and he was
being re-admitted. As a nurse, these are the situations where you feel helpless and wish you could do more. I did not see Shawn that day.

A few weeks later when I went to the hospital to interview Dean, I realized that Shawn was in the hospital room next door. After I was finished interviewing Dean, I decided to stop by and say hello to Shawn. I knocked on the door and heard a soft, frail voice from inside saying to come in. As I slowly and quietly walked in, I saw a pale, weak, bald man sitting up in a hospital bed and again I was speechless. He wore a nasal cannula for oxygen and an erythematous rash covered both hands. He looked exhausted. He was also attached to an IV pole with several medications and hydration continuously infusing. I quietly and respectfully said I was visiting another patient, and I saw that you were here, so I just wanted to stop to say hello and see how you were feeling. He was happy to see me, and he began apologizing profusely that he never got back to me regarding the interview. I felt so overwhelmed with emotions, and I said, “Shawn, please stop. There is no need to apologize. Your focus should be on getting better, and we can do the interview at another time.” He said, "We can do the interview now if you like." I was shocked and humbled at the same time but declined and suggested he get some rest but he insisted. Then I thought maybe he was lonely and having some company would be welcomed so I confirmed that he wanted to conduct the interview and he said “yes.” I reviewed the study once more and he signed the informed consent. The interview began when I asked him to tell me about his “Experience as a father with a cancer.” I was not able to place a “do not disturb” sign on the door but his nurse was also aware of the interview and decided not to interrupt unless it was medically necessary. The following is
an excerpt from the interview that gives a description of his experience as a father with cancer:

A couple of weeks ago when we found out that my leukemia was back, some of the doctors and the nurses were portraying it as a potential death sentence. I’m choosing not to see it that way because there is hope still but the first thing I thought of when I heard that was, my son can’t grow up without me. My dad died at a time I thought was early, when I was 23, but this is way earlier. This would be unacceptable. So I got to fight on.

I asked Shawn if there was anything else he would like to share with me regarding being a father with cancer. He then began telling me about precious moments he shared with his son on his 5th birthday. The interview lasted approximately 30 minutes and then came to a close.

This interview was the hardest I had done so far. Seeing Shawn in his weakened state and being overwhelmed by his willingness to participate was more than I could handle at that moment. Shawn had only been diagnosed six months before the interview, and he spoke of his many struggles and how this diagnosis had negatively affected his life but he showed such strength and a desire to live for his son. I did not ask Shawn how I should send him the transcript. I decided to contact him at a point when he was feeling better. Several weeks later, I received news that he was doing well and would soon be discharged. I was careful in deciding when to contact him regarding the transcript, so I reached out to my colleague regarding his status, and she told me he was doing well. I called him, he gave me his email address and suggested I send it there and I did. He did not respond for several weeks, and I followed up with a phone call, but he did not answer. A few days later, I received a text message from him stating that he received the transcript and that he will review it over the weekend and send his feedback, but he never did. Again, several weeks went by with no response. Shortly after, I was working in the
BMT clinic and realized he had a scheduled appointment. I decided to talk with him then and I did. He again profusely apologized, and I again told him that it was okay as I know he is dealing with so much. He said that the transcript was accurate and that no further clarification was necessary.

**Jose**: I was re-introduced to Jose by a colleague that works in the supportive oncology clinic. I cared for him about a year ago when he was receiving IV chemotherapy. Approaching him regarding my study would have just been a continuation of our already positive rapport. He is a Hispanic male and was the youngest participant in my study. He was 30-years old, diagnosed with stage IV renal cell carcinoma and he was the father of three children, aged 15, 13 and 3 years. He was being followed by the genitourinary oncology team. I reached out to my nurse practitioner colleague who works with that group and asked her to make the initial introduction of the study at his next appointment and she agreed. I also saw Jose that day. When I informed him of my study, he was impressed that I was working on my doctorate and indicated that he wanted to help me in whichever way he could. Jose had lost significant weight since I had seen him last and had this chronic pain to his abdomen and back for which he was followed by the supportive oncology team. It seemed that his condition had worsened but he was overall in good spirits. After a quick screening to verify that he fit the inclusion criteria, I discussed the details of my study. Like Shawn, he was interested in the topic and was more than willing to participate. He wanted to schedule the interview at his next appointment in two weeks, so we did. However, he did not show up for that meeting. I reached out to both my colleagues to ask if they had seen or heard from him and neither of them did. A week later Jose called the supportive oncology office telling them that he
was in pain. He came in for a visit and was admitted to the hospital for pain management. Several weeks went by, and situations and circumstances prevented us from communicating. I followed up on his status with my colleague to ask for his permission to call him. He agreed and I did. It was challenging to coordinate schedules because of his frequent hospital admissions for pain management. Nonetheless, on one of his admissions, he contacted me and suggested that we conduct the interview. He said any day in the afternoon worked best so we scheduled it that Sunday evening.

When I met Jose at the hospital, he looked comfortable as he sat up in his hospital bed. He was wearing pajamas and a beanie (a type of knitted hat). Pain medication flowed into his body from an IV pump and pole that stood nearby. His nurse came in prior to the interview to administer some anti-nausea medication that Jose had requested. He introduced me and informed her why I was there. As she left she said she would put a “do not disturb” sign on the door. I was impressed by her generosity and consideration. Jose and I were now free to conduct the interview in private without being interrupted. The study details were reviewed once more and he signed the informed consent. The interview began when I asked him to tell me about his experience as a “Father and having a cancer diagnosis.” Within the first minute, Jose teared up and began crying. I sympathized and asked if he would like to stop the interview, but he agreed to continue. After a brief moment, he was ready to resume. With a different approach, I asked him to start from the beginning, when he was first diagnosed. He was more at ease, and the dialogue began to flow. The following is a brief passage from his interview that describes his experience as it relates to being a father with cancer:

Being a dad and going through this, I try to be as strong as I can. I put on a face like I’m smiling every day, which is not a fake smile, it’s a genuine smile, but in
the back of my mind, I have thoughts like I’m not going to see my son graduate from college. I’m not going to be able to get to my daughter’s wedding and dance with her. I might not be able to marry my fiancé, you know? It’s a thing where you’re putting in so much and you feel like you’re doing so little. That’s what it is. It’s like a roller coaster ride. I love my kids and my fiancé, and it makes me so mad that I have this.

The interview lasted about 50 minutes, and it was full of details about his struggle with cancer, pain, failed chemotherapies and the side effects, and frequent hospital admissions but he also spoke of his love for his children. It was evident that he wants to stay alive for them and to continue his life and living. Similar to all the other interviews, I asked Jose if there was anything else he would like to share with me regarding being a father with cancer. He responded by saying not really and that we had touched on everything. I thanked him for his time. I told him that his story was compelling and that it may help other fathers and nurses caring for fathers like himself. After the interview ended, I asked him how he would like to receive the transcript. He opted for an email as well. We hugged, I wished him the best, and told him I would keep in touch. After leaving the room, I took the sign down, informed his nurse that I was finished and thanked her. On my way home, I thought of thin and frail his body had become. Several weeks later, I sent him the transcript and not long after that he texted me stating the transcript was “excellent.” No further clarification was needed.

Charlie: Charlie is another patient that my nurse manager suggested. He is Hispanic, 34-years-old and a young father of an eight-month-old baby. His diagnosis was stage IV urachal cancer, a very rare cancer and was receiving weekly chemotherapy. It was challenging to approach Charlie at the cancer center because his treatments only lasted an hour and he was always drowsy after receiving Benadryl as a pre-medication. Due to the situation, I had to ask my nurse practitioner colleague to make the initial introduction to
my study and to ask if I could contact him by telephone to discuss my research if he is interested. He agreed. I called Charlie a few days later. I did the initial screening over the phone and determined that he was a good candidate. I discussed the study, answered his questions and formally asked if he would like to participate and he said yes. Charlie decided that the best time to conduct the interview would be at his next oncologist visit because he was not scheduled for chemotherapy that day. They were changing the regimen. As planned, I came prepared to conduct the interview but was informed by Charlie that he needed to get his chemotherapy and would not be able to conduct the interview. I understood and we rescheduled.

Charlie was a tall and heavy-set young man that had an acne-like rash on his face, a side effect of his chemotherapy. On the day of the interview, he wore a black t-shirt that said “FIGHT CANCER” in bold white letters and black sweatpants. He looked comfortable as we sat adjacent to each other in the conference room. There was a “do not disturb, meeting in progress” sign on the door to maintain privacy and limit interruptions. The study details were reviewed and he signed the informed consent. The interview began when I asked him to tell me what his “Experience has been like as a father having cancer.” Charlie was composed and articulate as he told his story. Unlike the rest of the parents who were fathers before their cancer diagnosis, Charlie became a father after his diagnosis. Sperm banking was not an option for him and his wife as it was too costly, so from the time of diagnosis and commencing chemotherapy, they had a month where he and his wife decided to try to get pregnant, and they did. It was a story that warmed my heart. Charlie gave so many details on how much he loves his son and embraced fatherhood. He talked about his struggles but he also stated that receiving a cancer
diagnosis had many positive outcomes in his personal life as it helped him put many things into perspective. The following excerpt is a brief sample from his interview that gives a description of his experience as a father with cancer:

I break down, and I curse this damn chemo and this damn cancer, you just get tired. It’s been over a year now when this whole thing started. You put this premeditated notion in your head that you know what, this is nothing. I’m going to beat this and it’s going to take me a year. In a year’s time I’m going to be fine and in 6 months after that, as time went on, I started seeing that that’s not factual, it was not realistic. It was me being very optimistic but unrealistic at the time because I just didn’t know any better…It worries me that I still have this thing and I don’t know how long it’s going to be…I don’t know if I’m going to have this for another year, another 2 years. All the research that I’ve done about urachal cancer, they say it lasts from 2 to 5 years, treatments could go on. Now I’m looking at my son being 4 years old by the time I’m done with this. Worst case scenario, I’m not around, then what?

The interview lasted approximately an hour and ended by me asking if there was anything else that he wanted to share about being a father with cancer that he did not address in the interview. He responded ”No” that actually we covered a lot. I thanked him for sharing his experience, and he thanked me for allowing him the opportunity to share his experience, and he hoped that it would help others. I asked Charlie how would he like me to send him the transcript for his review. He suggested via email and gave me his email address. I thanked him again, we hugged, there was something about Charlie that was so warm and genuine, and we parted ways. Charlie received the transcript several weeks later and it wasn’t long before he contacted me and stated that he read the transcript and “everything seems perfect.” There was no need for further clarification.

Dave: Several months went by before I was able to recruit another participant. My colleague who worked in the supportive oncology clinic told me about Dave. He was a patient that comes to the clinic for pain management related to his stage IV pancreatic cancer. I asked her to make the initial introduction of the study, to ask Dave if he would
like to learn more and if it was suitable for me to contact him via his mobile phone. She did, and he agreed. A few days later I called him, made the initial introduction of myself, gave more information regarding my study and did the initial screening. Dave was 45 years old and has an 11 years old son. He was recently diagnosed with stage IV pancreatic cancer and was told he only had six months to live. I discussed the purpose, benefit, and risks of the study, and he expressed a deep interest in participating. Two days later, I realized Dave was in the infusion suite receiving his chemotherapy and decided to visit him there to do a formal introduction. Oddly enough, when I saw him, he looked familiar, like I had seen him before. His son was also with him that day. I briefly reviewed the study again, addressed any questions or concerns he had and then asked when he would like to conduct the interview. Dave’s treatment schedule did not coincide with mine so we decided to meet outside the cancer center. We planned to meet the following Friday in Prospect Park, Brooklyn close to his home.

Dave and I met in Brooklyn as planned. It was a beautiful sunny morning, there was a fresh breeze, and we both found a bench under a tree to conduct the interview. He was a tall, slender African American man and he wore a faded black t-shirt and jeans. After he signed the informed consent, I asked Dave to tell me what “This experience being a father with cancer, metastatic cancer” has been like. Dave felt comfortable in talking about his experience, however he worried that his words weren’t enough to capture and verbalize his story the way he wanted to. He did express deep concern for his son’s future should he die and not be around to be his father. The love he has for his child was also evident. The following is a small excerpt from his interview that gives a brief description regarding his experience as a father with cancer.
I can’t die, I don’t want to die. I don’t fear dying, I’ve just got to be here for my son, at least until he’s 21 or at least until he’s of an age where he can understand life and take care of himself. That’s my main concern for him. Just being there for him as a supportive father for whatever floats his boat so to speak, or whatever he wants to do in life.

At the point where I thought we could end the interview, I asked Dave if there was anything else that he would like to share with me that we may not have touched on about being a father with cancer. He responded by saying “there’s a million, I mean a quadrillion things you probably can’t even touch on as far as fatherhood and this disease.” The interview continued for several more minutes, and lasted approximately 50 minutes. Dave felt as though there were more details he wanted to share with me but had difficulty recalling everything. I told him we can always schedule a follow-up interview if he desires. In the meantime, I informed him that I will transcribe his interview, analyze and synthesize the data and send for him to review via email as per his preference. I thanked him, and he was more than happy to have talked to me. We gathered our things, he escorted me to the subway, we hugged and went our separate ways. Several weeks later, I forwarded the transcript for Dave to review. He responded via text stating that it was fine. No further clarification was needed.

Rob: Two months went by before my previous nurse manager told me about Rob, a patient who brings his two young sons when he comes in for chemotherapy. A review of his chart shows that he has refractory multiple myeloma and is a single father of two children, ages 7 and 10 years old. I reached out to my colleague who is more involved in the management of his care and asked her to make the initial introduction of the study. She did, he was intrigued and wanted to learn more. The next day Rob had an appointment at the cancer center, so I decided to introduce myself and discuss the study
then. He is a tall and slender African American male. He was a very pleasant, well-dressed man in a long-sleeved shirt and slacks and very articulate when he spoke. He is also the oldest participant in this study at age 60-years old. The study was described in detail, he had the opportunity to ask questions or express concerns, and verbalized a desire to participate. A date to conduct the interview was scheduled in two weeks at his next appointment.

As scheduled, two weeks later we met. A “do not disturb, meeting in progress” sign was placed on the conference room door. Rob and I sat across from each other as I reviewed the study once more and he signed the informed consent. The interview began when I asked Rob to tell me of his “Experience as being a father and having multiple myeloma.” Rob shared his experience and spoke fondly about his boys and how much he enjoys spending time with them and being their father. He is aware, and has accepted the fact that there is currently no cure for multiple myeloma and knows that he will eventually die from this disease but he doesn’t fear dying because of his religious beliefs. However, his primary concern was dying and leaving his sons with no one that will care for them and guide them along the spiritual path that he wants them to follow. The following passage describes his love and concern for his children as a father with cancer.

As a person and being realistic, I know that we all have to die. So put that in perspective of the multiple myeloma situation, I tell myself the little metaphor that we die sooner or later. What this has done, my disease made me start thinking that not necessarily this has to happen, but I am now in a group that you would consider sooner instead of later but this is just my attitude after I found out that I have multiple myeloma. I'm not scared of dying…since we don't have a cure for multiple myeloma, it's nothing that makes me fearful, however, what it has affected is that since I'm a single parent with two boys, 7 and 10, it does make me feel a little apprehension every night when I go to sleep because I don't know if I will wake up. So as a result of that, my boys and I have spoken and we are very good friends, so they know, they have certain numbers to call if when we wake up in the morning dad doesn't wake up…My treatment has been on hold because of
my situation. I don't have anyone that I feel confident enough to leave them with since I see the seriousness of the procedure that I have to take. Since I'm a Jehovah’s Witness, I don't take blood transfusions, so there is a good possibility that I won't make it out alive. I can't just go in and don't worry about what happens with my boys because they're so important to me. I'm not going to just leave them with anyone and certainly if I do go in and I don't leave them with anyone and something happens, I don't want them to end up here and there in the system. I love them too much for that kind of situation. So, as a result, I've been putting off my much-needed procedure until I find a real solution that is best for them.

The interview with Rob lasted for an approximate hour and ended because he had another appointment elsewhere. We shook hands and parted ways. Several weeks later I contacted Rob to inform him that the transcript was ready for his review and asked how he would like me to deliver it to him. He opted for a printed copy. I met with him the very next day at his appointment and handed it to him. He said he would review it and get back to me. Several weeks went by, and I had not heard from him. I decided to call him and after a brief conversation, he verbally informed me that he read the transcript and that he agreed with it. There was no need for further clarification.

**Antonio:** A couple of weeks after meeting Rob, my colleague who works with the lung oncology team informed me of Antonio. A review of his chart revealed that he has stage IV lung cancer. I asked her to make the initial introduction, and she did. The day she made the initial introduction to my study she informed me that Antonio was more than willing to participate and that I could speak to him today if I had time. I took the opportunity. He was a tall, overweight Hispanic male with dark features. He looked comfortable and listened intently as I explained my study in detail and determined he fit the inclusion criteria. He is 47-years-old and had two daughters, 11 and 18 years of age. I gave him the opportunity to ask any questions or voice concerns but he had none and
agreed to participate. Unfortunately, Antonio was not going to be at the cancer center for a few weeks, so we opted to conduct the interview later that week at his home.

    As planned, I met Antonio at his home. The study was reviewed once more and he signed the informed consent. He was wearing a white t-shirt, black shorts with white socks. We sat adjacent to each other, he was on the sofa and I was on the rocking chair with the tape-recorders on the coffee table between us. The interview began when I asked him to tell me about his “Experience as a father with cancer.” Antonio began talking and recalled many intimate details of his struggle, fears, concerns, and hopes among many other emotions regarding himself and his two daughters. His fight to continue to live to be able to take care of, guide, protect, love and provide for his daughters was so evident.

    The following is a brief excerpt that gives description of him as a father with cancer.

    I realized I was in an oncologist office, and she told me there is a 98 percent chance you have cancer, lung cancer. I said lung cancer? I’m not a smoker. I smoked an occasional cigar in a wedding, but I’m not a smoker or a drinker...I was angry. I was like why me? Stage four lung cancer? Why me? I kept asking them how long do I have to live. They weren’t giving me much time because it was a rare cancer that had already spread outside my lungs...I asked them if I have a fighting chance. I told them I have daughters. Who’s going to raise my daughters? God can’t take me and leave my daughters alone in this world. I’ve been taking care of my daughters forever.

    The interview with Antonio lasted approximately two hours. I was surprised at how much information he gave and how comfortable he felt talking to me. He shared many details about his life and being a father with cancer. I did not anticipate being there that length of time but I wanted to give him the opportunity to share his story in whatever length and detail he wanted to. I did have somewhere else to be (I had another participant interview) so after an hour and 45 minutes I asked him if there was anything else that he wanted to share with me that we did not already cover. He stated “I wish I had my father
here to be able to talk to him.” Antonio did not have the best relationship with his father when growing up and he died from a massive heart attack before they had the opportunity to become close. I couldn’t imagine the pain he must have been through and is still going through as he continues his battle. The interview ended. I thanked Antonio profusely for allowing me to enter his home and for allowing me to listen to intimate details of his life and struggle as a father with cancer. I told him he has given me a lot of work to do, we both chuckled and that I will contact him when the interview is ready for his review.

Several weeks went by before I contacted him. I asked him how he would like for me to get the transcript to him. He also opted for a hand-delivered printed copy. He had an appointment at the cancer center the next week so we agreed to meet then and he was given the transcript. Several weeks went by and I had not heard from him, so I contacted him. He told me that he has not been feeling well. I told him to take his time, recover and that he can review the transcript at his convenience. Several weeks went by before I heard from him but he informed me that the transcript was fine and that I could proceed. No further clarification was needed.

**Woody:** Around the same time I was informed about Antonio as a potential participant, my previous nurse manager informed me about Woody and suggested that I contact him. A review of his chart revealed he was 38-years old, recently diagnosed with stage IV renal cell carcinoma and has four young children, ages 15, 12, 8 and 6. Woody was the first potential participant that I approached and did the initial introduction to the study. I introduced myself and explained why I wanted to speak to him and asked if I can have a few moments of his time. I told him I was doing a research study looking at fathers with cancer and his name was referred to me. I asked permission to discuss my study and he
said sure. The study was described in detail. I stressed that participation is completely voluntary and will not affect his care here in any way. I gave him the opportunity to ask any questions or voice any concerns of which he had none. I asked if he would like to participate, that he can think about it, however he said sure and agreed at that point in time. I asked when he would like to conduct the interview and he was free the next Friday. We planned to meet at the cancer center at noon.

We met as scheduled. The study was reviewed again and he signed the informed consent. We sat adjacent to each other with the tape-recorders on the table between us. The interview began when I asked him to tell me what “This experience has been like for you, as a father with cancer.” He made it clear that his children are his top priority and that his life revolves around them and whatever they need. The following is a brief excerpt that gives a description of this.

It's been a little hard you know, mostly more because I just recently found out but you know, everything is based around my kids. So I just spend more time with them, I try to do the best you know, just in case this doesn't work out for me. So far, everything has been good. I'm new to this, so, it's, how can I put it? I don't tell them anything so they don't know, they won't know. I'll probably take this with me, and I won't say anything about it but so far so good, everything is looking up and up. So, medication in one hand, prayer in the other and that's it. I'm new, I do not know too much about this cancer. I just want to keep it away from their ears, spend as much time as I can with them and you know, my family, my love ones, I appreciate the small things now.

The interview with Woody lasted approximately 35 minutes and ended the same way. I asked if there was anything he would like to share with me regarding being a father with cancer to which he responded “No, not really. I think we touched everything.” We continued talking for a few more minutes and then we ended the interview. I told him I will take a few weeks to transcribe and analyze the interview and will contact him when it’s ready. I thanked him, shook hands and parted ways.
A few weeks later, the transcript was ready for Woody to review. I called him and left him a message but I never heard from him. I decided to meet him briefly during his next chemotherapy infusion and give him a copy. Three weeks later I saw him at the cancer center, and he verbalized that the transcript was accurate. There was no need for further clarification.

**Thematic Analysis**

Thematic analysis refers to the process of uncovering the themes that occur frequently in the text that gives meaning and understanding to the experience or phenomenon that is being studied (van Manen, 1990). To accomplish this, I listened to each tape-recorded interview and transcribed them verbatim. This was a long and arduous process but I opted to do this to search for the deeper meaning by becoming familiar with each interview, the subtleness in each participant’s voice, their emotions and to stay as close to the raw data as I possibly could. As each transcript was read, key notes, words, and phrases were underlined or written along the margins that represented the narrative descriptions within the dialogue in relation to the experience. These key notes, words and phrases in accordance with van Manen’s (1990) data analysis method, gave description to the phenomenon being studied. This line-by-line analysis allowed for the uncovering of similarities in each participant’s story. These similarities or narrative descriptions were also color coded, for example, “live longer” was coded in yellow as I associated this color with living and life. These similar descriptions were then placed together to form clusters that captured the meaning of the phenomenon. This process facilitated uncovering the essential themes that gave the description and understanding to the phenomenon of dying in fathers with advanced cancer when death is imminent.
The above techniques allowed me to describe and understand each father’s personal experience and what this means to them. Initially, there were 15 clusters. According to van Manen (1990), describing the phenomenon through the art of writing and rewriting allows for a textual reflection of the participants’ life world, concretizing the understanding of the experience and creating meaningful relations to the physical and mental being. The fourth step in van Manen’s (1990) process allowed me to accomplish this. It provided me with the tools, the narrative descriptions that captured the meaning and gave understanding to the emergent themes the fathers discussed. The third step in this process, reflecting on the essential themes is linked to step four. Through the art of writing and rewriting by reflecting on these narrative descriptions, I was able to group the similarities that allowed the themes to emerge. After re-reading and re-writing, eight themes were identified that gave description and understanding to the lived experience of fathers with advanced cancer. The eight identified themes included: live longer, reaching milestones, financial security, making memories, fatherhood, maintaining normalcy, finding strength and support and dealing with challenges. After further reflecting and rewriting, it was found that “reaching milestones” could be collapsed into “live longer” thereby creating seven themes.

**Essential Themes**

The uncovering and identification of these themes, discloses the evolving meanings and imagery of the fathers’ lived experience and phenomenon under study. Through the inquiry of the lived experience of fathers with advanced cancer, the following seven themes were uncovered: live longer, financial security, making
memories, fatherhood, maintaining normalcy, finding strength and support, and dealing with challenges.

Each transcribed interview, inclusive of the seven themes was sent to each participant for clarification and review. They all felt that the themes were reflective of their experience as depicted in their interview and personal story. The seven themes were also confirmed with an expert researcher who felt that they were also accurate and reflective on the participants’ experience as a father with advanced cancer.

**Establishing Rigor**

The fifth step of van Manen’s (1990) research process is maintaining a strong relevance of the phenomenon. Referring and constant re-orientation to the research question allowed for this and maintained rigor. This allowed the true phenomenon to emerge without being side tracked, introducing speculation, settling on preconceived notions, self-reflection, self-indulgence or abstract theories. This avoided deviation, guessing, and biased opinions from tainting the study (van Manen, 1990). This was accomplished by maintaining a strong association and interpretation of what was discussed within the interviews, reflecting and relating back to the phenomenon. Self-conducting the interviews, self-transcribing verbatim and immersing myself in the data also promoted this. In doing so, the phenomenon allowed me to “meet with it, go through it, encounter it, suffer it, consume it, and be consumed by it” (van Manen, 1990, p. 153).

The criteria to maintain rigor and establish trustworthiness focuses on credibility, dependability, transferability and confirmability (Lincoln & Guba, 1985). Credibility was established by having each participant review their transcript for accuracy and validation of truth, allowing them to make changes and clarifications as necessary. The transcripts
were also read independently by another expert researcher and there was a mutual agreement of the themes that emerged. This promoted dependability and confirmability. Describing the exact methods of data collection, its analysis and interpretation give detailed description on how to replicate the study. This promotes dependability (Lincoln & Guba, 1985) as well as reliability (Cook, 2011). Re-interviewing if necessary to seek clarification also adds to the reliability in qualitative research. Transferability refers to the ability to transfer the research findings and methods or its applicability from one group or setting to another (Lincoln & Guba, 1985).

Examples from the participants’ interviews continued to further establish rigor of the research process as it gives description to the emergent themes. The following gives the narrative descriptions of each theme as it allowed me to describe and understand the lived experience of the fathers with advanced cancer where death is imminent. The phenomenon would fail to exist without these themes and the themes would fail to exist without these descriptive narrations from the ten participants.

**Theme 1: Live longer**

All ten participants expressed the need to live longer for their children’s sake and well-being as well as theirs. The theme of live longer encompassed three sub-themes. They include: 1) receiving medical treatments and following the regime proposed by their oncologist, 2) being healthy and making lifestyle changes as well as 3) being alive for several milestones that pertained to their lives and their children’s lives. The hope is that they will be alive until their children are grown, independent and able to take care of
themselves. The following phrases captured and gave description and details to the theme of live longer.

**Sub-theme 1: Medical treatments**

**Sam**, with a diagnosis of multiple myeloma, an incurable cancer, saw his life and future as it pertained to the ages and well-being of his children. He also focused on their mental health, re-assuring them that because of the advances in medicine he would not die soon. He stated, “I always looked at the treatment in regards to their (his children) life…it’s treatable, it’s not like I’m going to die tomorrow or in a couple of months I told them…the treatment is excellent.” He also felt that with all the advances in medicine that cancer is becoming a chronic disease. He states,

> When I first started hearing about it (multiple myeloma) in the 70’s, it was like a death sentence but now it seems like it is shifting as, you know, cancer, how do you treat it, not how are you going to die from it. At least that’s what it has felt like for me…even in the past five years they have discovered new drugs, five years from now, ten years from now so many new things will have happened that it should be okay.

Sam is hopeful for a cure. He talks about a friend that had non-Hodgkin's lymphoma (NHL) and according to her oncologist, is now cured. He is hopeful for the same one day. He states,

> There wasn’t a cure at the time when she got it 15 years ago but through advances in medicine, one day she went in to see her doctor and he told her that she is cured and that she doesn’t have to come back for another five years…that’s what I’m hoping for one day.

**Joe** was diagnosed with stage IV pancreatic neuro-endocrine cancer. His primary goal is also to stay alive till his children are old enough to take care of themselves. He made that clear when he stated “I just keep my emotions under check and stay alive you know, till they’ve grown up maybe a little. I’d hate to die before they’re, before they’re 20 even.”
He is also currently receiving chemotherapy and reports feeling better. He stated, “Since I began treatment I think I’m feeling better.”

Dean was also diagnosed with multiple myeloma and he expressed grave concern to live longer for his children. He states,

Anytime someone tells you that you have a disease that’s going to end your life, it’s a very hard thing to accept. First of all, from my standpoint, I have young kids which makes it worse. I can’t afford not to be here you know, I don’t want my children to not have a dad, they’re so young…The fact that what I have is hopefully treatable and could allow me to stick around for a little while longer has made it a little easier to deal with…Many things go through my mind, like I never wanted to be a father, have children and not be there to see them grow.

He also talked about receiving treatments and the hope that it will extend his life for a few more years.

I’ve been in treatment, the treatment is going well...should give me a bunch of more years, so knowing what you have been, makes it a little easier to deal with the fact that they can treat you, and you’ll still be around.

Shawn was diagnosed with Acute Myeloid Leukemia (AML). He was one of the two most sick and frail participants in my study. At the point of this interview, he had failed all previous cancer treatments, only had a partial response to his allogeneic BMT and was currently admitted to the hospital for relapse of his disease. His future seemed bleak as his doctors were still trying to decide what the next steps were to treat his AML, but his overall goal is to stay alive and live longer for him and his son. He states,

This particular admittance is different from all the others. The others were all some schedule for me, whether it be a chemo or a bone marrow transplant but this round right now, I was only supposed to be there for a few days but it’s now been over two weeks. I just had chemo, and they’re still trying to figure out what the next steps are going to be because my transplant wasn’t entirely successful. It’s a problem. So, I think things are still being figured out…I’m willing to go to a study at Cornell, which could pretty much help me depending how things progress.
Shawn’s options at this point are limited, but he remains hopeful. He states “we have to find something. I’m still hopeful that something is going to work out, that something good could still happen here.” He seems to be fighting a losing battle, but he refuses to give up the fight as evidenced in the following statement,

A couple of weeks ago when we found out that my leukemia was back, some of the doctors and the nurses were portraying it as a potential death sentence. I’m choosing not to see it that way because there is hope still, but the first thing I thought of when I heard that was, my son can’t grow up without me. My dad died at a time I thought was early, when I was 23, but this is way earlier. This would be unacceptable. So I got to fight on.

**Jose** was the second most sick and frail participant of this study. He was also the youngest father. His diagnosis was stage IV renal cell carcinoma. Like Shawn, Jose knew his cancer was serious but understood he could extend his life for an unknown amount of time if he continued his treatments. He said,

I got to take this seriously. It’s not a thing where it’s going to be gone the next morning. That’s when I become arrogant and stupid in a way. I’ve got to take care of myself…This thing I have is awful. It’s a deadly, deadly disease and it’s not something that the doctor said he can’t fix. He said it’s treatable, and that’s all we could be grateful for, of it being treatable. If I don’t take care of this then it becomes a deadly disease, and it becomes me hurting myself and hurting others.

He was also grateful for the advancement in medicine. He knew that if it weren't for that, he would have died already. He stated,

I feel like if this was in the 1970’s I wouldn’t be here in probably three months. You know what I mean? Now we’re in the year 2014, the advanced medicine, that’s crazy. They didn’t find a treatment for kidney cancer till 2009. It’s called Votrient. So that was the first thing they tried for kidney cancer and then these other drugs started popping up. Right now I’m blessed for the time I got.

**Charlie**’s diagnosis is stage IV urachal cancer which is a very rare cancer. As he puts it, “when I got diagnosed it was a huge hit as it would be to anybody, to get diagnosed with cancer, with urachal cancer that’s incredibly rare, with stage IV urachal cancer which is
even worse.” He raises concerns regarding how much time he has to live and like Sam, is hopeful for a cure. He states,

It worries me that I still have this thing and I don’t know how long it’s going to be. I have no idea. Urachal cancer, there’s no type of research on that. There’s no timetable to say, you know one of my wife’s friends had breast cancer. She got to the point where they knew how many more treatments she needed. The doctors told her, you need four more treatments, and you’ll be okay, I’m dying for that day to come. Hey, four more treatments and you should be good. I’m craving that so much right now, just because I don’t know if I’m going to have this for another year, another 2 years. All the research that I’ve done about Urachal cancer, they say it lasts from 2 to 5 years, treatments could go on. Now I’m looking at my son being 4 years old by the time I’m done with this. Worst case scenario, I’m not around, then what…but whatever it is, I have to move forward. I have to be there for my son.

However, regardless of his prognosis and how much longer he has to live, his main goal is to be cured and cope as much as he can. He stated, “My immediate goal is to get over this and cope with it as much as I can.”

Dave was diagnosed with stage IV pancreatic cancer. His concerns of living longer focused on his child and being there for him especially in light of the fact that his oncologist told him that his time is limited. He states

I don’t know about my future. The doctors told me that I have six months to live, and then everybody’s telling me no, that’s not true…I still can’t grasp this thing. I can’t die, I don’t want to die. I don’t fear dying, I’ve just got to be here for my son, at least until he’s 21 or at least until he’s of an age where he can understand life and take care of himself.

Rob was diagnosed with multiple myeloma, and he is at the stage where he has failed several chemotherapies and is now on a clinical trial. Multiple myeloma’s progression of the disease can be measured by the M protein levels that circulate in the blood. As he reports, there’s a spike of this protein, and his oncologist changed his chemotherapy. He stated, “the spike that it took was not the best, so that’s one of the reasons they had
changed my medication, and now they're giving me Pomalyst because they wanted to try something else that they’ve never tried before.” Rob has accepted that there is no cure for this cancer and knows that he will eventually die from it, but he is still hopeful that his medical team will do whatever is necessary to keep him alive for as long as possible. He states,

I know for one thing, I have to die, that's a given. I have to die and second, with my disease, since there is no cure, I will never know when it's going to happen…I am not stressed out about it. The things that stress me most relate to my boys but I think from my knowledge, which is not much about these medical things, I think that I’m doing all right and I am depending on the skill of those that’s taking care of me. I hope that they're (oncologist) skillful enough to do what's needed to prolong my life as much they can.

**Antonio** was diagnosed with stage IV lung cancer. He recalls when he was informed of his diagnosis. He was outraged.

I was angry. I was like why me? Stage four lung cancer? Why me? I kept asking them how long do I have to live. They weren’t giving me much time because it was a rare cancer that had already spread outside my lungs…I was angry because I never abused drugs, I’m not a smoker, I’m not a drinker. I had an occasional Heineken in my late 30s and early 40s when I was working but like I said, I’ve never abused my body.

His oncologist didn’t give him much hope. His cancer is terminal with a poor prognosis.

“He (the oncologist) didn’t seem too optimistic. He told me it (lifespan) could be two days, two weeks, two months. Not even a year, not even two years. He said to me it’s in your body. He was telling me that it has already spread.” However, despite this bleak news, all he could think about was living for his daughters, being there and providing for his family. He was not ready to die. He states,

I asked them if I have a fighting chance. I told them I have daughters. Who’s going to raise my daughters? God can’t take me and leave my daughters alone in this world. I’ve been taking care of my daughters forever.
His thoracic surgeon was able to perform a surgical procedure that could give him longevity. In reality, at this point, that was all he wanted. “All I ask them for is longevity.” After the surgery, he did not waste time initiating the recovery process. He wanted to gain strength and build stamina so he could be discharged from the hospital, begin chemotherapy, and be on his way to recovery and longevity. He recalls,

I did the physical therapy on my own, I got up off the bed and I walked…The next day, instead of doing the one and a half lap I was supposed to do, I did three and a half laps, running and walking up and down the stairs...I did the physical therapy that night, I did it Saturday and then Sunday. I did six laps around running with my daughter on the machines, walking up and down the stairs...I told her (surgeon) I want to go home on Monday...I prefer to be home on my king size bed, let me sleep in my bed...so I can rest... She came on Monday, and she saw I was doing physical therapy...They removed the tubing and she said you can go home. I went, I came home that Monday evening. I slept as much as I can and Tuesday I started chemo.

Woody is a young father of four children with a recent diagnosis of stage IV renal cell carcinoma. He focused on receiving his chemotherapy and is having a clinical response for which he is happy. He states,

After that (being diagnosed), as you know it's been this treatment and you know, I have a good doctor. So, he’s obviously doing his part, and I'm trying to do mine. That's it…the last news I got from the doctor says that there’s been shrinkage all over. So, yeah, that’s the, you know, that definitely makes me feel better…so far so good, everything is looking on up and up. So, medication in one hand, prayer in the other.

He will do whatever it takes to live longer, as he puts it “anything to prolong my time” to be able to see and spend time with his children. He states, “Honestly, I don’t keep track at all. I don’t care how many of them (chemotherapy cycles) it takes. I just got to do what I got to do to win the fight and stay alive for as long as I can.”

Sub-theme 2: Being Healthy
Eight fathers spoke of being healthy and making healthier lifestyle changes as it pertained to improving their diet, increasing their daily exercise, decreasing stress and getting sufficient rest. The following gives description to this sub-theme of live longer.

Sam made some lifestyle changes since his diagnosis. He began eating healthier and continues to bike around New York City. He stated,

I lost weight because I started eating better…I cook more. I’d make my breakfast because I also changed my diet, you know, no sugar, no carbs right, so I have eggs and sautéed vegetables in the morning…I’ve done it (biking) since 1991. I’ve always ridden my bike in the city. Since I moved to Brooklyn, it was always the easiest, and fastest way to get around, so I’ve always had a bike and always done it.

Joe also expressed a desire to live a healthier lifestyle. Before this interview, he was diagnosed with diabetes secondary to his pancreatic neuro-endocrine cancer and was recently hospitalized. He thought he was healthy and stated “I was healthy, I thought I was healthy, ” but for him this was a wake-up call to seek nutritional advice and try to overcome diabetes by eating healthier. He states,

I think the diabetes was a wake-up call, you know, I got to do something better, something healthier, whatever I am doing wrong…Health-wise, they never asked about my diet and they never discussed what I should be eating. I thought I was eating well for the two years since I’ve had this. I saw a gastroenterologist the last few months, and she warned me that one of the outcomes of this cancer is developing diabetes. I thought maybe I could have put it off if I ate a proper diet but I never got nutritional advice.

One of his other interventions to remain healthy is to get sufficient rest after his wife picks the children up in the afternoon. He states, “I get a certain amount of rest after they (his children) leave.”

Dean talks about resuming a healthy lifestyle. He states,

That’s another thing I am going to try to do when I get out of here (the hospital), just try and keep myself healthy, try and eat a little better and now that this is
done (BMT transplant) I want to start to get myself back into shape because I think that helps you fight anything better, when you’re in shape. I think that’s why they tell me that I’ve done well fighting this stuff up to this point so far because I used to take care of myself in a decent manner and keep myself in decent shape.

He also talks about his stresses at work. He is a lieutenant in a family court and he wishes for the day when he can retire and doesn’t have to deal with that stress anymore.

The grind is what wears a lot of people out. It’s just the grind, and I say this all the time, if I didn’t have to work every day, I would be able to fight this much better. Just because I would get more rest and less aggravation from going to work you know, all that shit adds, it adds up...it’s a very volatile environment that any moment it could just explode. That puts a little stress on you.

Charlie expressed concerns about being healthy as a goal. He states,

Getting healthy is number two, because if I wasn’t, from what the doctors told me, and from everything that I’ve gone through, I’ve done some pretty hardcore chemo in the last year or so, and if my body wasn’t as healthy as I thought it was, I probably wouldn’t have been, or I wouldn’t be as strong as I am now.

He has been through several chemotherapy regimens, and he wants to flush the chemicals from his body and live a healthier lifestyle for him, his wife and child. He states,

Just live a healthier lifestyle. Get all these chemicals out of me...all the chemicals, and I was very much, I would always cook at home. I just don’t have the strength anymore to do stuff like that, so I want to return to that. Again, I was, I’ve always been heavy set. I’ve always been on the heavier side, but I was healthy. I wasn’t sloppy. I wasn’t, I never had any heart problems, diabetes or anything like that. Knock on wood. To this day, I haven’t got any of that. I just want to go back to living a healthier lifestyle for myself, for my wife, for my child. It’s true when they say you have a baby your mentality changes completely, and if you have a baby while you have cancer, it’s even worse.

Dave has been taking a partial holistic approach to treating cancer, living longer and being healthier. He states,

I’ve been trying holistic medicine and stuff. I mean, what can I lose at this point? I’m trying anything and everything you know? That’s what the fight is about with me. I’m just more concerned about prolonging my life and having a decent quality of life and just really spending a lot of time with my son, just being there with him. It’s hard. The battle that I’m facing is the use of holistic medicine over the use of Western medicine. I don’t like the way that chemotherapy makes me feel
and the holistic herbs boost my energy… I’ve been using turmeric, shark cartilage and some other vitamins and supplements and they make me feel so much better compared to the stuff at the hospital. It’s so draining.

**Rob** talked about receiving herbal treatments since being diagnosed but he had to stop this after gaining custody of his sons and becoming a single parent. He states,

> After I was diagnosed, I would take trips to Florida because down there I was getting help with herbal stuff… I would get my treatment here for five days and then I would be off for three weeks which allowed me to go down there but after I got the boys, I couldn’t do that anymore.

He does, however, continue to eat healthy and do his daily exercise routine. He states,

> I try to have a healthy diet and eat as best as I can. I also do exercises every morning. Every morning I’d do my stretching, my sit ups, my leg raises and when the weather is nice I’ll go outside and jog. I have to keep myself healthy, that’s how I look at it. I have no choice. I have to do what I have to do. I have to do my part.

He also expressed concerns about getting secondary infections. Multiple myeloma is cancer of the blood and these patients are more prone to infections. A few months prior to this interview, he was admitted to the hospital for pneumonia and shortly after that he got the flu and was re-admitted again. He recalls,

> A few months ago I caught pneumonia, was admitted to the hospital, and they kept me for four days and the following month, unfortunately, I caught the flu, but the thing is I have the flu vaccine. So they don't know why I caught the flu. So they believe that they have to, the reason I think I'm coming in here on Fridays and Saturdays is because they're trying to make sure that my immune system is strong enough to fight against any flu or pneumonia.

As a result, the boys have a strict routine after they come home from school.

> They come home, and they know what the schedule is. When you come home, the first thing you do is you take your clothes off, because with my health situation, they go to school, and they're playing with other children, and unfortunately a lot of parents have to leave their children at school even if the child is sick… So as a result how I try to deal with the situation with me and my boys is that every day they have to change their uniform because I don't know what goes on in school. So when they come home, the first thing they have to do is take their clothes off and put it in the laundry.
Antonio talked about his diet before his diagnosis. It consisted of steak, bread, and soda. He states, “I used to love to eat steak and burgers and all that...my only habit was drinking a lot of soda and eating a lot of bread.” However, since being diagnosed and with the help of his older daughter he has made some dietary improvements. He recalls,

She was doing research. She said dad, this is what's right for you, this is what you need to eat. They called my uncle in Puerto Rico, my uncle in Brazil and they send me what's called soursop which is, which is in Spanish called guanabana. It's expensive down here and by the time we found them, my uncle had sent me the vitamin. He also gave me the plant...I still have the plant in the freezer. He grows it in his yard. I was eating the, I'm eating the fruit when they send it and then the plant I use it as a tea. I also take the vitamins.

He also changed his diet,

I changed my diet, so I got more into eating fish, drinking natural juices for the antioxidants, I've always been a big drinker of water...I started looking at it as a person that has diabetes. I lost my brother and sister to diabetes three months apart from each other in their 30s. So, that's the way I’ve looked at it.

He remembered eating ribs from a local restaurant that made him sick.

It got me sick, and when I mean sick, it didn't give me diarrhea or anything like that, what it does, it leaves me constipated, it gives me stomach pains, I can't digest it...I have to be more focused on what I eat and what I do and what I, you know, just the little things. Whereas before, I would just get up, shower, brush my teeth, go to work, bam, that's it, come, I'll eat steak sandwiches, I can't do that anymore. Now, I'll limit intake of the food I eat. I eat a lot of salmon, tilapia, shrimp which I read is all good for cancer, fighting cancer cells.

Antonio was always into fitness. He continues to exercise as tolerated as well as keep all his doctor and chemotherapy appointments. He explains, “I went to all my appointments. I got up as early as I can to do my exercises. I have the stretch bands. I have my bike, I go swimming, basketball, you know, I like to throw a football around every now and then when my friends come to see me.”
Woody also focuses on aspects of being healthy. Since diagnosed, he has resigned from his job due to chemical exposure and stress. Now he can relax and focus of getting better. He states, “I left the work alone, it's, you know, I worked as a security guard in one of the buildings and you know, the smell, the asbestos, all that I had to get away from that, you know. So it was best, you know, so for now, I can relax.”

He was always a health conscious person even before his diagnosis so he could tell something was wrong. He stated,

I’m a guy that used to walk six miles to work...when I see that my endurance isn’t the same or my stamina isn’t the same, I knew there’s something wrong you know, especially when I eat well, drink water all the time, don’t drink soda, you know, I take care of myself pretty well to know when something is wrong.

Apart from his endurance and stamina dwindling, he was also losing too much weight.

He consulted a nutritionist, and his weight has been improving. He states,

She told me to drink juices and supplements that are healthy, gave me vitamins that’ll help to gain weight, you know, stuff like that. You know, certain vegetables that I should be eating, it's also with a proper diet that I’m, I’m happy I’m gaining weight. I feel good you know, that’s what important to me.

His appetite has also been improving. “I'm healthy. I eat a lot of vegetables, and I also play around a little bit, you know, with what’s not healthy but, I'm happy with it...I've been eating real food. I eat anything, if it is delicious, I’m doing it...I’ve been living.”

Sub-theme 3: Reaching Milestones

Five fathers spoke of reaching milestones, whether it’s related to their lives or their children’s lives. The following gives description to this sub-theme.

Sam gave great detail in his hope for his future as well of his children. His hope was to live for a very long time but he realizes that his cancer will steal that away from him. He kept referring to a lifespan of 15 years that revolved around his entire future and the time
he had left regarding his children’s lives. He stated “I wanted 40 or 50 more years out of my life so that 15 years (his new anticipated life span) is pretty short…it puts a timeline on your life.” He hoped to be alive to see his children when they are older and have accomplished certain milestones in life. He is also looking forward to getting older and all that entails. He stated, “If I have 15 more years, the older ones would be out of college, the younger ones won’t, you know.” He also exclaimed,

My God! I’m not going to see them when they are grown and that was a weird feeling…The assumption was that I was always going to be there until they were grown and now this happens, they’re so young. I want the older part, the part of life I just took for granted. Like once they are in school my wife and I can have fun and visit them in their apartments and we can be grandparents but I’m not going to let myself think about that stuff now. I will concentrate on the present…I look at them on different scales and I say that in fifteen years, the older ones would be out of college and hopefully confident and out working and that’s about the time you can deal with losing a parent. For my youngest child, she would be fifteen or sixteen and my four year old would still be in college. These are the two that I worry about the most and then I think, probably none of them will have children by then, they probably won’t even be married. These are the hard parts and it’s more of a realization that, if I take care of myself and hopefully with new advances in medicine, I can still be around, I can still be hopeful for that kind of stuff.

**Dean** wants to live long enough for his children to be old enough to take care of themselves as well. He hopes to be alive to see them graduate college and get married. He stated,

In retrospect you’d like to be able to enjoy life with your children, but when you get sick, you worry about who is going to take care of them. I am not worried about me I just want to be here for them. See them graduate from college, maybe get married and live a happy life. If you’re healthy and life is normal, you take that part for granted because it’s going to happen. Once things change, you realize you’ve got to fight because you want to be around for some time to make sure that they are on their way and is more knowledgeable about life. Nobody wants to leave their children where they have no one, without them knowing or without them being at the point where they can, at least, take care of themselves. That’s not the reason I brought them into the world. I wouldn’t want to do that to them or have my wife be in that position.
Shawn’s hope for the future was simple. Though he is hopeful and wants to live as long as possible, his goal for the future was simply to take his son to the new Star Wars movie on opening day in December 2015. He states “for a goal, just like I said, I’m not giving up. I have got to take my son to see the new star wars movie on opening day next year. I’ve got to do that...next Christmas, I got to be there.”

Jose had hopes of living longer to accomplish some milestones as well. He wished to marry his fiancé, see his son graduate from college and dance at his daughter’s wedding but he knew this was not going to be a reality. He stated,

I have thoughts like I’m not going to see my son graduate from college. I’m not going to be able to get to my daughter’s wedding and dance with her. I might not be able to marry my fiancé, you know? It’s a thing where you’re putting in so much and you feel like you’re doing so little. That’s what it is. It’s like a roller coaster ride. I love my kids and my fiancé, and it makes me so mad that I have this.

Antonio’s primary goal is to live as long as he possibly can to see his younger daughter get married. His focus is on his daughters. He states,

My goals are to live to see my youngest daughter get married. I want enough time, I ask God to give me enough time, as much time as he gave me with my oldest one, that's all I ask from God every night, give me longevity. I want to enjoy my little one the way I enjoyed my oldest one. And my oldest one, I still want to enjoy time with her. I want to give her away at her wedding but if I can't, I want her to understand that I love her very much. I am proud to be her father and no matter what happens I'm always going to be there in spirit, but I want the same time with my little one.

Theme 2: Financial Security

Eight fathers spoke of financial issues in some aspect. They all wanted to maintain financial security by having sufficient funds to cover daily expenses, pay their bills, secure their children’s future and or have a little extra for miscellaneous purchases. The following phrases give description to this theme.
**Sam** expressed financial concerns in regards to his children’s college and tuition funds. He described it as a wake-up call. It’s made him realize that he has to start planning ahead for things like this, for his children’s financial future. He exclaimed,

> The assumption was I was always going be there until they're old, and so the change is like, Oh boy! I might not be there for a long time. So I have to build up a little support for them, and it's not just going to be me working, and I can help you out and do whatever, it's like, oh boy I have to leave some stuff behind, make sure that there are savings, and it's probably a more mature way that most people look at when they have kids. So if the timeline is this, then the youngest is just going to be in school. So I need to make sure these savings are in order…now I realize, oh we got to start it now, and I'm going to make sure these things are in place now.

**Joe** shares a similar situation like Sam in regards to his children’s college savings. He stated “as far as college savings, I, I’m way behind…just got to save more for the future I guess.” He also has financial struggles on a day to day basis. He’s been on disability since his diagnosis but he receives his pension, so that has been of some financial help.

> There is a waiting period before you can go on disability, you have to wait five months to get the money. So, I had to use my sick time and my vacation time with the post office and I had a pension from the police department, so it was a great help.

His younger son noticed the financial struggle and offered to find a job to help out.

> I remember my children asking me why am I not going back to work. The older one noticed more than the other, especially when he’s asked for certain things and we’ve had to say no, that we can’t afford it. Then the younger one would ask for things too of which we’ve also had to say no, then he said to me, don’t worry dad, I can go to work. He also told his mom not to worry that he could get a job and help out.

Another significant expense for Joe and his wife is child care so it makes Joe happy that he can help out in that setting. He has been taking care of his sons on a daily basis while his wife is at work. “She does not have to pay for child care. Hopefully, I would be around for a lot longer to do that.”
**Dean**’s financial issues revolve around wanting to retire and spend time with his family but he can’t because of these financial responsibilities.

I would like to retire right now but I have to wait a while. In two years, I will qualify for my pension, my disability and just take care of my family. I don’t want to be rich, I don’t need to be rich, I just need enough money to pay my bills and make sure my family is all right, that’s all I want.

He currently works two jobs. “I work four days a week at my regular job and then I work Saturday night on my second job” as a security guard in a local restaurant.

**Charlie** has several financial concerns. His immediate ones revolve around his living situation and his son’s future. At present he is unemployed and on disability. He states, “right now I can’t financially be there for my family. I can’t work 80 hours a week and make $100,000. Now I receive $1,000 monthly from disability, and it sucks.” Because of his current situation, he was forced to move in with his in-laws. He states,

Not having financial freedom is very upsetting. It worries me because I used to work a lot, and get paid very well and had money in my pocket and had money to save, I don’t have that anymore, so it is scary. I was never one to live paycheck to paycheck...I’ve always been the breadwinner at home. I’ve always been the one that worked. I go out, work and bring money and make sure we live comfortably and not being able to do that is stressful. Not being able to go out and say, hey I’m going to go work because that’s what I do is incredibly stressful...I’m supposed to make sure my family’s okay, and they're comfortable, and they’re living fine and not being able to do that is frustrating, and it’s tiring, and it gets to be too much.

His other financial goal is to secure his son’s future regarding his education. He states,

Another goal is to solidify my sons’ future. I grew up in a Catholic family so one of my primary goals is to provide Catholic schooling for my child...All throughout high school, I went to Catholic school, so I feel like that’s the way to go. I need to save up for his education because it’s not cheap. It’s gotten more expensive as we’ve gotten older.

**Dave** works part time, and he wishes he had more money to do more or give more to his son. He states,
(I work) here and there as a flagger with ConEd...I'm on call most of the time, so they call me when they need me...when it comes to finances as well, it’s, it’s a problem, it’s a slight problem because financially I’m not that sound. I do the best I can or whatever with a small budget. You don’t need much with a child who just enjoys your company, the least and the cheapest things make him happy. I wish that I could do more...I wish I had more money to do more for him you know but like I said, money doesn’t make the kid happy.

One financial concern that Dave does not have to worry about is in regards to his child’s college tuition courtesy of his grandparents. He exclaims, “That kid already got university money set aside for him.”

Rob has several problems with his day-to-day living and expenses. He was not able to retire at the appropriate time and was not able to receive those benefits. He states,

This (divorce) is going on for many years, and it's starting to affect my work, they’re taking everything from me, I even had to give up my apartment...all I had to do was to work three more years, and I would have gotten full benefits and everything. When my boss realized my situation, the post office offered, fortunately for me, offered me an early out and so I took it, but it hurt me financially a lot because it was nothing but I had no choice, I needed to survive.

He also had financial issues keeping up with his child support.

I couldn’t keep up with my child support. So what I did was, I went down to the place on 42nd Street, to get them aid, social security. She was getting $500 for each of the boys at the time and at least it was some financial help since I didn’t have any money. So this situation forced me into taking the early leave though I wanted to save my three years. Then I fell behind in my child support, every month I had to give her $600 for each child.

Now that he has the children Rob reports difficulties in getting a bigger apartment for him and the boys. This was due to bad credit. He reports, “I couldn’t pay my credit card bill. So my credit is bad and the thing is, my largest credit bill is a bill from a cell phone that I had given to their mother when we were married.”

Antonio is currently on disability. He states “I get something from my union. I get social security disability but the social security disability they give me in a month, I used to
make in a week, on a slow week.” His older daughter is in college, and he pays for those expenses. He states “I pay for it...I paid for her tuition, books, I’m still paying for it to this day.” His younger daughter is going to a private Catholic school and when he was diagnosed, they were supportive and helped them financially. He recalls,

Education was important to us and my daughter and my wife, they love Sacred Heart, it's an all-girl private school, and they were real supportive also. When I got sick, the first thing they told us was not to worry about tuition, not to worry about anything right now and that whatever we need, they raised the money to help us. They're an excellent community.

When his first daughter was born he remembered feeling a sense of responsibility of having to work and to provide for them and providing for his children has always been his primary goal. He remembers, “The first thing I thought about was I got to save money for my kids, and it's always been about giving my kids the best, so I did everything I could to give it to them.”

At his last job, prior to being diagnosed, he worked a lot. He associates getting sick with working this hard and not allowing his body to rest. He recalls,

I concentrated so much on working, doing overtime and you know, doing triples and doubles and in a way I always have that in the back of my mind, that that’s one of the reasons I got sick. It’s because I didn’t allow my body to rest. My family told me, Antonio, you’re working too much, you’re going to kill yourself. I was just working to provide my family with the best. Then we had our second daughter which made me even go more and work like a machine. I didn’t think about rest much. You know, there were days where I will go on two or three hours of sleep and be at work, then the next day three or four hours, five hours sleep and be at work the next day. There were days I worked 72 hours straight, come home, take a nap, and just work. My wife would pick me up at work, and I would sleep most of the time in the car on the drive back.

Woody did not report any financial concerns. However, he did resign from his job, and he is living on his savings. He states, “Whatever I’ve saved up that’s what I spend and live off.”
Theme 3: Making Memories

Nine fathers described spending as much time as they possibly could with their child or children. Receiving a cancer diagnosis made them realize their time is short, that there is a timeline, and they have to make every second count. These special moments and memories became more valuable and meaningful. Several of the fathers were the sole caretaker for a period of time that allowed them the opportunity to spend time with their children. The following phrases give description to this theme in regards to remembering these memories, spending quality time and making new ones.

Sam recalls time spent and the memories made with his first two children prior to his cancer diagnosis. It shows how appreciative he was to be their father. Those early memories mean so much now that he states there is a “timeline” on his life. He recalls,

I was a selfish father and I always looked forward to being a dad. I loved it. When the kids were born, they were small, and I was a video editor. We moved my whole business into our loft, and I would, I was Mr. Mom, stayed at home, cooked their food, and have fun with them. I’ve always felt very appreciative of every little moment spent with them.

As the two older kids grew and he had his two younger children, he felt more accomplished as a father and looked forward to spending every second of every day possible with them, making new and exciting memories. He states,

The older kids would visit their relatives in Brazil. They would go for big chunks of time and stuff like that and now with the two younger ones I get to be with them all the time you know, and now I’ve got my dream life as a dad, I can be with them and raise them.

He and his children have also been enjoying the summer; he says “we’re out and about being active. It’s been New York’s nicest summer ever.”
By profession, Sam is a video editor which he also uses in his personal life to capture these moments and memories so his wife and children will have them long after he is gone. He states,

I have tons of that stuff (photos and videos), and it's not that there is more or less, um, maybe I am more organized with it, whereas before I just acquired it, and I’m like maybe one day I’d get to it, you know. I did start to make a video for my wife that she doesn’t know about…it (my diagnosis) hit her so hard in the beginning.

He also reports having special moments with his youngest daughter at breakfast time,

“We’ve found out the youngest girl loves eggs so she wakes up with me and says “eggies, eggies,” so alright let's scramble eggs.”

Joe is separated from his wife and is currently on disability. Because of this, he can spend more time with his sons than he’s ever had compared to when he was working. Since being on disability, he has taken on a father caretaker role especially since his wife works and drops the children of to him before she leaves. He is grateful for this time and is enjoying making new memories. He states,

It's been great that I have been able to stay home with the kids for the last two years. I drop them off at school and pick them up in the afternoons. We also had a great time the past two summers. It's just fun to be a part of their lives more now than I have ever been when I was working…She, (his wife) goes to work at 7:30 and she drops them off to me. I have them most until 4 o'clock or even later some days…I take the kids to school and then I pick them up at 2:30 in the afternoon and bring them home, and they do their homework and I give them snacks or something…I am enjoying the time with them. It makes the day go a lot quicker when you see them, and I am seeing them a lot more than I did before I got sick.

He talks fondly about activities they shared during the summer. He states,

I play soccer with them so they know I can still play, you know, I am still in relatively good shape, not as well as them but, you know, we have a great time. We play baseball for hours and hours and I try to get them involved in other things. A couple of weeks ago we went to a water park…we play these little one against two games at the handball court, you know, I let them cheat. We have good times together.
As a father, he also enjoys sitting and observing them. It’s almost as if he is making his own memories that he will smile fondly of for the rest of his life.

Now that I have them all day I know it is going to be a long day. I got to put up with a little bit of aggravation and a little bit of fighting but I'm much more patient with them I think. I am used to their habits now, you know. It's great to hear the two of them talking or arguing amongst themselves, I just sit back and listen…I love sitting and watching, I don’t know how many Sponge Bob episodes I’ve seen with them in the last two years. I don’t mind watching the same ones over and over again.

Dean works two jobs, but he fondly remembers spending quality time with his son shortly after being diagnosed with cancer and had to have surgery. He was his caretaker while he was going through the recovery period. He states,

You know I enjoyed taking care of my son. When I first had the surgery I was home for a bunch of months, so, I took care of him when he started school. Got him up in the morning, got him ready for school, came home, took care of his homework, and hung out with him. I would try to take him somewhere most days, we would get some frozen yogurt or just hang out a little before going to the house. It was cool just spending the time with him.

Since being diagnosed with cancer, Dean is waiting for the moment he can retire and just spend the rest of his life with his family. He longs for that time when these precious memories and moments can be made with the ones he loves more than anything else in this world. He states,

It (cancer) helps you put life in perspective too. For me I can’t wait to be able to stop working and stay home and spend as much time with my family as possible, like I say, you never know how much time that is. People take it for granted you know. When somebody tells you that, you realize there could be a definite, you know, a definite end to that time so, you want to enjoy as much as possible, and that’s, that’s some of the best stuff in the world. Makes me happy, makes me laugh, I enjoy it, that’s what’s important, especially at this stage in my life, I have a family, and children, I want to enjoy that time. To me, that’s much more enjoyable.
Shawn worked as a freelance writer, and he was the principal caretaker of his 5-year-old son. These were the time they spent and shared many precious father-son moments. At the time of his diagnosis, his son was four years old, and he stated,

I was the main caregiver at the time for our four year old son. My wife worked a corporate job. I was a freelancer. So, I’ve been the one who often pick him up from preschool every day, and I would, we’d go shopping, and we’d go to the park for a while, then we’d go home. I’d give him a bath, and we’d make dinner together, and all these things happened, you know before his mom came home.

Shawn spent many days in and out of the hospital after learning that he had an aggressive leukemia that unfortunately did not respond to any of the treatments he received. During his time in the hospital, he and his son shared special memories by drawing for each other. He recalls,

One day, he sent me a drawing from school and the next day I sent a drawing back, and then we were drawing for each other...I did, I don’t know, a hundred pictures or something like that over the next few months. The first batch was all superheroes. We both like superheroes together. It was cool.

These drawings will be a memory his son will have forever to remember his father after he dies. Another memory Shawn shared with his son was watching all the “Star Wars” movies. It was around the time of his son’s 5th birthday. At this point in his battle with cancer, his leukemia was back, and he was waiting to be admitted again for an allogeneic bone marrow transplant (BMT). He recalls,

I was home for a month, from mid-June to mid-July, which was in some ways good because it was my son’s birthday and all that. The negative aspect of it was that I was waiting for a transplant and my leukemia came back before they can do the transplant on me. So, I had all kinds of just not good luck during that time but I showed my son Star Wars. My wife and I disagreed in the beginning, she thought that he was too young to see it but I’ve always felt that Star Wars opens a world of imagination and endless possibilities especially for a little boy, and I’m not around right now (was in the hospital), but he still has Star Wars. So, we would watch it together and now, like I was as a kid, he’s obsessed with the whole thing, and I think it gave him something, and I thought it would. So, he has Star Wars now.
Jose, like the other fathers also enjoyed spending time with his family. One of his main priorities after being diagnosed was “spending more time with the kids and trying to spend more time with my fiancé.” He elaborated,

    With the kids, I try as much as I can but we can’t do that much outside (it was winter), but we play video games a lot. A lot of video games, and with my fiancé we just watch TV together and talk about the day or talk about random stuff.

He reminisced about the past and remembered memories and shared moments he had with his children before his diagnosis with cancer. He states,

    Before my diagnosis, I was playing baseball with them, basketball too. Now that I have this, it’s hard for me to run or to shoot even a basketball because I am so weak. Before cancer, we would still hang out. We used to go to movies, restaurants and I was working.

Then he started remembering the beautiful time he shared with his three year old daughter.

    The biggest silver lining is seeing my daughter smile when she comes home from daycare and then says daddy where are you? That makes my night, my day, I love it...It’s my daughter man, that’s daddy’s girl. It’s an experience where I finally have daddy’s little girl and she’s always around me and always hugging me…Every other day we watch Frozen. She's goes daddy you’re my prince. I was like yeah, I’ll always be your prince...I watched that movie with her on Wednesday of last week three times in a row.

Charlie has an eight month old son. He is currently on disability and is the principal caregiver. While his son is too young to remember these memories that they share, they mean more to Charlie than words can explain or describe. He stated,

    I am the person that takes care of him on a daily basis because of my illness, which I guess in retrospect is a blessing...I can enjoy my son...I take care of him all day, so I’m able to learn his traits and learn what he likes, and what he doesn’t like and how to get through to him.
Charlie mentioned some future memories he would like to make and have with his son. He states, “I want to be able to look at my son and say, we’re at City Field, we’re having a hotdog and we’re enjoying a Met game together.”

**Dave** does not live with or near his 11 year old son. They live four hours apart. Since being diagnosed with cancer, with an estimated six months left to live, he was adamant about having his son stay with him over the summer. He wanted to spend as much time together as he could before he died and never get that opportunity again. He states,

> My parents wanted me to wait, to put it off, they said there’s going to be another time that you can get him but I didn’t listen. I was really adamant about bringing him down so, I did so against their will and we had the best time. I don’t get to spend a lot of time with my son as it is so I don’t like putting these things off especially when my time is short. Every moment, every chance I get I want to spend with my son, you know. That’s what makes me happy.

His son came down to Brooklyn from Utica and spent half the summer with him. They were both thrilled to be able to spend these precious moments with each other. He fondly remembered, “he always hugs me out of the blue, and just enjoys being with his dad, this is the first time we spent in a long time together, he’s happy to be with me, period.”

His son loves going to the beach, so they did that frequently when he was in New York.

> He loves going to the beach every day when he’s here in New York because there is no ocean where he lives…These are the things that he’ll remember, spending time with his dad and the enjoyable moments that we spent together.

At this point, Dave is allowing his son to be and do whatever he likes. He is not the disciplinarian anymore. He wants his son to fondly remember his last moments with him, however, many more moments that may be. He states,

> I’m more sensitive to his feelings now. He can do whatever he wants when we are together. I want him to have the best time he can have at this point and I’m just letting him be a kid. You don’t have to be mature or anything. If you wish to be a baby, you can be a baby. Whatever you want to do at this point, he will always be my baby, my little boy…I realize that he cherishes every moment that we spend
together. He doesn’t want to go to the park or anything. He simply wants to stay with me, like stay around me all the time.

_Antonio_ loves spending one-on-one time with each of his daughters. He states, “I spend as much time with my daughters as I can, one on one, we have date nights.” He recalled a few memories,

I had to take my daughter to the movies, my oldest, after the movies, she wanted to go out to eat, and to the Comedy Club. The following night I had a father-daughter dance with my little one, she had a great time and I had the best time too. I always try to do things with my daughters. I’ve always been about my children and spending as much time as I can with them even when I worked those crazy hours. I always found time to go with my youngest daughter to Mass on Thursdays, when she has Mass at school and I try to go up to Syracuse as much as I can to spend time with my oldest daughter Elsa (a pseudonym).

Now that Antonio isn’t working, it allows him even more time to spend with his daughters.

Now I have more time and the freedom to spend more time with my daughters. That’s the reason my wife didn’t want me to go back to work. She doesn't know how much longer I have to live so her thing is for me to spend as much time as I can with my kids, even though I've always spent time with my kids. It's always about my family…I’ve spent more time with my kids since I’m not working.

He and his daughters also take a lot of photos on their mobile phones. He exclaims, “We've always had memories, we’ve always taken pictures, and I gave them their phones and they take pictures now.” Conducting this interview at Antonio’s home allowed me to see how many photos he had on his phone as well as in his home.

_Woody_, like all the other fathers, spends as much time as he can with his children. They are his top priority. Throughout his interview this was evident. He states,

Everything is based on my kids...I just spend more time with them, I try to do the best you know, just in case this doesn’t work out for me...it’s just about spending more time with the kids, that’s all it is. So as much time as I can get out of it (life), that’s all I care about. I’m spoiling my children, I don’t say “no” as much anymore. You know, anything they want, that I can afford, I get it. It's all about them, I don’t do anything more for myself anymore, it’s just all about them,
whatever they need. I help them with their homework, just listen to them no matter what it is they're talking about. I want them to feel that they are the most important part of my life.

He is there for them no matter what and will do whatever it takes to see them happy.

They could call me for the silliest things, “I want a sandwich,” I will leave from wherever I am and take it to them. I enjoy seeing them happy. I am available to them all the time. Even though I'm not living with them, I’ll go and stay over on the weekends or whenever they need me. Sometimes I’m with them every weekend, I’d go over there maybe four days after my treatment just to make sure I don’t have any chemo in me. We would go out, talk, watch TV, do simple things. Sometimes we’d all go out and get breakfast, you know, just spend as much quality time as I can with them.

**Theme 4: Fatherhood**

All ten fathers spoke of being a father and of fatherhood. They spoke of how much they enjoy being a father to their children, the life lessons, the nurturing and guidance that they are trying to instill and imprint on their children knowing their time is limited. Several fathers also remembered and mentioned their fathers. The following phrases give description of this theme.

**Sam’s** view on fatherhood focused more on how he enjoys being a father and how grateful he is that he has the family he always wanted. He states,

> I always looked forward to being a dad. I loved it...I've got my dream life as a dad, I can be with them and raise them and I love my wife, and we're the family that I always dreamed and hoped for...I am lucky I have my kids and I don’t have any part of that family life or fatherhood missing that I would long for.

**Joe** and his wife are separated and his children live with her, but he takes care of them during the day while his wife is at work. He enjoys these moments and the role of fatherhood. He states, “I take the kids to school and then I pick them up at 2:30 in the afternoon and bring them home and they do their homework and I give them snacks or something.” He also feels happy that he has been able to help his sons with their
homework and feels that because of this, they are doing better in school. He states, “I can help them with their homework all the time and I think they are in a much better place in school since the last two years.” He is also a proud father. He states “I am so proud and happy with the way they’ve grown up.” As a lesson on fatherhood, since taking care of his sons, he says that he has developed more patience, “I’m much more patient with them I think.”

Dean is the father of three children. His fathering focus is on his first-born son, his 6-year-old whom he favors and shares a special bond. He states,

I might treat him maybe a little different, but I think any father treats their first born son a little different...I don’t treat him like entirely different and stuff like that, but I would say every once in a while I probably favor him a little. I think like I said, any father does that with their first born son because I think every dad who wants a family is always trying to have a son first.

Dean doesn’t know how much time he has left to live, so he’s been trying to guide and nurture his son into a “routine.” He states,

Like I said, I’ve been attempting to get him into a good routine because it is important...you want to get kids in a good routine because you know, hopefully it carries over. Just getting up and going to school, come home, do the homework, just a routine like that because some kids just don’t get into a routine.

Dean has also been talking to his six-year old and nurturing him about being a good big brother to his younger siblings. He states,

I want to able to be there for all of them but at least I know he is a little older so as long as he is good, I know he’ll do the right thing. Because I’ll be telling him all along, I tell him now, you’re the big brother it’s your job to look out for your brother and your sister. That’s just the way it is. The way I look out for you, the way I take care of you, and if something happens, it’s up to you to step in and do for them what I do for you, because if I can’t do it, somebody’s got to do it. So, he’s been, he’s pretty good with them.

On a different level of nurturing and guidance, Dean has been teaching his 6-year-old son about being polite and having manners.
I’m a better father now at this age than if I had been a father when I was younger. At my age, you realize how important the time you spend as a parent and how important your input is because in a couple of years when you see how your child acts and behaves, you realize it’s all due to you…for the most part, your children are a carbon copy of what you are…My son is very polite, he says thank you a lot. He is such a good little kid which is what I want him to be. I want to be able to be here to grow him up into a good man, you want to put in as much time as you can because you just never know.

Shawn was the principal caregiver for his son, and after his diagnosis, he spent most of his days inside of a hospital. Since then, parenting for him has for the most part been long distance, either via the telephone, Skype or Face time. He states,

Well, just because I’m not around doesn’t mean I’m not a dad. There are times I’ve called home, and my wife is having a lot of trouble with him, he won’t get in the bath or whatever. So, I’ll get on the phone, and say, “Listen, take your bath. Do you want to watch your cartoons later? Take your bath right now.” So, you know, I can do some parenting long distance on the phone or Skype...we did a lot of um, a lot of face timing. Every morning before school, we talked a little bit.

Jose also gave guidance and encouragement to his older boys. He never hid from his boys that his disease is terminal. He gave them a pep talk in preparation for when he is no longer alive and able to care, nurture or guide them. He states,

You guys have to be men right now and step up to the plate because the things that I did before, I’m going to need your help. I said Dom (pseudonym) you’re going to be turning 15, that was at that time, and I said, Joe (pseudonym), you’re going to be turning 13, so you got to understand guys, that this isn't a joke. Your mother’s going to be going through a lot of stress, she’s going to work, she’s going to be picking up the baby from daycare, she’s going to be doing a lot of stuff that you could help her with. I said please don’t use my disease as an excuse for why you’re doing badly in school or why you didn’t do your homework or why you didn’t do your chore or why didn’t you do this or why you didn’t do that…You know some kids use that as an excuse and take advantage of it. I said it’s not going to be fair if I’m not able to do the work and you guys are just in your room watching TV. I said you can mop, you can sweep, you can do the dishes, feed the pets. It’s easy stuff.

He is also a proud father. His thirteen year old son is “part of Rosie’s kids, he’s a dancer, an actor, a singer. He’s going to be on the Halo Awards.” Then he has his three year old
daughter with whom he is absolutely in love. He states, “it’s my daughter man, that’s daddy’s girl...I’m so happy I get to experience this...that little girl makes my day.”

Charlie became a father after learning he had a rare stage IV cancer. He has an eight month old son and he is proud to be able to experience this. He states, “He’s teaching me how to be a parent...It’s incredible that I have the opportunity to do this...it’s made me very proud to be a father...it’s very rewarding.”

He recalled how happy he was when he found out that he was going to be a father, and how much he wanted to care and provide for his son. He remembers,

I was incredibly happy that my wife was pregnant and that I was going to have a son. I always wanted to be a dad. I’m really good with kids...I love children and now that I am a father, nothing matters but him. Once you hold that little person that’s an extension of you in your arms nothing else matters, nothing, myself included. It’s what's best for him, so it’s very important to stay with the mentality that you’re responsible for another being. It’s very important to me.

Charlie credits cancer for allowing him to have his son. At the time he was diagnosed, he and his wife had a month before starting chemotherapy where they decided to try and conceive since sperm banking was too costly and not an option. They were successful, and he was thrilled. He states,

It’s awesome, I wouldn’t change it for anything in the world and it’s funny because people have asked me, well if you would have, if I needed cancer to have my son, would I do it all over again and I respond and say absolutely, no problem, no second thought in my head. I would take cancer again to have my son...I’m emotionally there for my son. I probably know my son better now than I would if I didn’t have cancer.

Charlie has embraced fatherhood and is taking his role very seriously. He is also currently unemployed and is rethinking whether he should resume working because he doesn’t “want to miss out on my son.” He states,

Now I’m a dad. Now, I’m a father. That’s what’s important, is making sure that he’s okay. I want him to be better than me. I want him not to have any regrets. I
want to be able to give him what he wants. I want to guide him on what we feel is right and as long as I can be around to provide some guidance and give him whatever he needs, he can succeed in life.

**Dave** is another father that does not live with his son. They live miles apart so they aren’t able to see each other often and spend as much time as they would like. They communicate on the phone, and they were able to spend quality time together this summer. This distance, however, does not hinder Dave from being a father. He expressed great concern for his son’s future and well-being when he is no longer here to take care and nurture his son. He says,

> My main concern is my son’s future and how this (cancer) is affecting him. I worry about how his life and future would be if I’m not around. I’m concerned, who’s going to be the next influence in his life and you know, how he’s going to deal with his anger and pain when I go.

Since being diagnosed, Dave has been there more for his son and is supporting him mentally and emotionally. He states,

> My primary concern is just being there for him as a supportive father for whatever he wants and needs. In his early years, I wasn’t always there 100 percent, but I always stayed in touch with him...the main thing, I want him to know is that he has his father and that I love and support him 100 percent.

He is teaching his son about life’s lessons.

> The other day he asked me when it is okay to cry and I said well, basically whenever you feel like, if you need to get it out of your system, its okay. You’re not any less of a man if you cry. Tears are good.

**Rob** is a single father to his two boys and it is evident that their well-being, instead of his, is his top priority. He states,

> After I was diagnosed, I would take trips to Florida because down there I was getting help with herbal stuff but at that time the boys were with their mother. So after they told me that the boys have to be with me, it changed my lifestyle. I can no longer go to Florida because I have to care for them...There is a procedure called a bone marrow transplant that I was supposed to have years ago but I haven’t taken yet because it requires me to be in the hospital for weeks and now
that I have the boys, I have to be here for them. I have to stay here, it’s a whole new different ball game…My treatment has been on hold because of my situation. I don’t have anyone that I feel confident enough to leave them with since I see the seriousness of the procedure that I have to take. Since I am a Jehovah’s witness, I don’t take blood transfusions, so there is a good possibility that I won’t make it out alive. I can't just go in and don’t worry about what happens with my boys because they’re so important to me. I’m not going to just leave them with anyone and certainly if I do go in and I don’t leave them with anyone and something happens, I don’t want them to end up here and there in the system. I love them too much for that kind of situation…Until I find or come up with a solution that is best for them, people say but if you die, they’re going to lose you anyway and I understand that but that’s only one point of view. My point of view is that when I go in and I am being treated and I am laying on that bed, I need to feel good knowing that wherever they are, they’ll be fine if I don’t wake up.

Being able to care for his sons has also undoubtedly given him a sense of joy and pride.

I'm of the age now where their life is what matters to me. Everything else has to go on hold because now it's their time, and that’s the way I deal with my boys, and it makes me happy...I'm very happy with my two boys. I'm happy, and that’s the way we are...I have two sweet boys, and they're challenging, but I accept the challenge. They are great. I couldn't ask for better kids.

One of his primary concerns is dying and leaving the boys with no one to take care of them. He prepares them for his death. He states,

Since I'm a single parent with two boys, 7 and 10, it does make me feel a little apprehension every night when I go to sleep because I don't know if I will wake up. So as a result of that, my boys and I have spoken and we are very good friends, so they know, they have certain numbers to call if when we wake up in the morning, dad doesn't wake up, you call these numbers...That is the only thing that is fearful to me, in fact every night when I go to sleep, I’m hoping that I will wake up the next day. You know we go and we pray when we go to bed at night, but I am always concerned with whether I will wake up or not...because now it's not just me, it's my two boys and me.

He is also hopeful that he can find a partner that will love his kids and will care for them if he should die. He states,

I told them that one of the solutions is getting married again and they didn’t have a problem with that. I explained to them my situation. I said, I'm sick, and you never know what might happen. If something happens to dad and he doesn't wake up, I want you to be able to stay with somebody that will love you as much as I do or, at least close to it…I’m the one with those two boys and I’m the one that has
to decide what I think is best for them. I may be gone in my situation and then my boys will be left out in the open.

Since gaining custody of his children, he has taken his caretaker and educator role very seriously. He states,

Their schooling, because that’s my life, every day is the same for us from Monday to Friday. (I) Get up at 5:30, wake them up at 6:00, get dressed, go to school, and when they are in school, that is when I make my medical appointments…Every day after school we do homework, and when they are finished they can play whatever games or watch a little TV, cartoons or whatever they want to watch. Then it's bedtime, and then the same thing starts over 5:30 the next day.

Rob is aware of his age and his boys are his primary concern. He is also aware that his past is what has made him who he is today. He states,

It's just how I deal with my boys and how they develop in life. That’s my primary concern, I look at everything that has happened, and I view it as a challenge, and as far as my disease is concerned, I'm trying to do the best I can for the benefit of my boys. I've lived, I'm 60 years old. It's their turn. Since we haven't missed their turn and if I've got to go, I've just got to go as long as I can leave them in good care...Whenever I get into talking about my experiences like this, it's been years of things that has molded me. In fact I think it was all of it, whether it was bad or good, it has molded me into a different person. So with that and my disease, that's what I am today, I'm dealing with that, and with my experiences as a father. With this disease and with them being so young, time is a factor because it’s time for them to get to that age where they can be on their own more.

Rob and his ex-wife have had a troubled marriage and divorce however they are keeping it civil for the sake of their children. Protecting his children from this negativity is paramount to him. He states,

We remain better friends now than when we were married…We try to keep this away from them. All they know is, I love mommy, and I love daddy, so they don’t have a problem with it, and that’s what I want the boys to see that, that’s okay, mom and dad, we don’t live together but we have no problems.

Antonio is so in love with being a father that it is evident in how he cared for and nurtured his daughters. He remembers the challenge when he first learned of his diagnosis. He recalled,
God can’t take me and leave my daughters alone in this world. I’ve been taking care of my daughters forever…everything to me was always about my kids, and when I got sick, that’s the first thing that popped into my mind, who is going to care for them.

His top priority is caring for his daughters and providing for them. He states, “I take care of my kids, I do what is necessary. I’ve always been the type to put my kids first in everything I do.” He’s always had a special bond with his older daughter. He took care of her since she was a baby. He had a difficult time telling her that he has cancer, but she already knew. He recalls,

She said, dad you have cancer, don’t you? My daughter felt it. We've always had a bond because when my wife gave birth to my daughter, she had postpartum depression. She wanted to give me a boy, and she had a girl, and she didn’t hold her or fed her. So I was the first one to hold her, feed her, change her, talk to her.

He also recalls a moment when his older daughter was a baby and as a father, he stepped in and saved her life.

She has asthma, and when she was ten months old, she stopped breathing. It was 2 am and her mother woke me up, she was having a panic attack so I told her to call 911. I jumped in the shower with her so the steam could open up her little lungs. When we arrived at the hospital, the doctor told me you know, you saved your daughter’s life, that was smart thinking, it opened up her lungs. I stayed awake with my daughter and for three nights straight, my 10-month-old slept with me watching Archie Bunker and all that you know, that's why she has this bond with me.

He has always been the one to take care of his daughters in every way possible. They always look for him when they are sick and as their father, he’s always there.

I've always been the one to take care of my kids when they're sick. My kids always come looking for me when they're sick, it’s always I want daddy to take care of me, both of them are like that. It’s always dad, can you give me this, can you give me that? It’s always been that way. I’m the one that always sit with them in the hospital. I guess that’s why they’re like that with me now that I’m sick. Both of them are very close to me.
Antonio believes in spoiling his children. He’s worked hard and gave them everything he can as long as he can afford it. This can also be looked upon as a life lesson. He states,

I’ve always spoiled my kids. You know, I don’t believe that you can really spoil them if you give them what they deserve. I’ve always given my daughters everything, as long as they are doing well in school, and they respect us, and they know the difference when I say no, that I don’t have it, and that's what's good about my kids.

As a father and being realistic in light of his diagnosis, Antonio prepares his daughters for his death. He remembers a conversation he had with his older daughter.

The thought of me dying, because that was the thought in my head every day for the first couple of months when I was diagnosed, if I’m going to die, who’s going to take care of my kids. I had to prepare them for that. I knew that we had to talk and that I had to tell her the truth. I said Elsa (pseudonym), I need you to do me a favor, that’s my oldest, I said if daddy will die, you’re strong and you know the way I raised you, so don’t feel sorry for me because I’ve lived. I want you to support your mother because she's going to need you, okay, I’ve been with your mom since she was 14. Your sister is going to need you. You're strong, I raised you to be my kid, you’re my daughter and you have your father’s heart. You’re going to be the one that's going to take care of this family. She hates talking about me dying, she hates talking about me being sick, so after a couple of months she sat me down and said, dad, don't let cancer define you, you define cancer...We’ve always had a strong bond, I’ve always had a strong bond with my kids and what this has done is made them look at reality, and my oldest, I think it’s hit her the hardest...she hates talking about me dying and when we talk about what has to be done as far as insurance, life insurance and what the plans will be if I pass away. She hates talking or hearing about this, my little one too.

**Woody**, just like the other fathers, his primary fathering focus is supporting his children in whatever their endeavors are and protecting them. He has decided to never let his children find out about his cancer diagnosis as a way to keep them safe so they can have a complete home and childhood. He states,

I don’t want them to have resentment towards their mother and say dad passed away and you weren’t together, and then they become rebellious and don’t listen or do their schoolwork. I want to keep their home like a complete home for them since I am not there as much...I just want to see them smiling all the time and the whole point is to protect them at all times so I do not want them to hear about this at all. I just want to keep it away from their ears.
He is aware that they will find out sooner or later. He said, “When they find out, they will find out and it’ll be ok, hoping they will be old enough to understand and come to the conclusion that at first he never told us because he was trying to protect us, you know.”

As a father, since his diagnosis, his role as a disciplinarian changed. He states,

   I’ve loosened up dramatically you know, I am not as strict with them anymore. They control everything now. I'm still there disciplinary-wise, but I'm very loose, I'm very open and I listen to them more. I take more from them, see how they feel about things and let them express themselves and I'm more understanding now, so I think that's helped me out a little bit in that aspect.

He talks about being around for his children and being a supportive father.

   As long as I'm around, I'm going to try to be the best father and help them accomplish whatever they want to do. I care about their education, but I also want them to be happy. I want them to do what makes them happy, I’m not going to live my life through them, I want them to live their lives, and do what they want to do, it’s all about them…My goal is to stick around for them and make them happy, spoil them when I can, do whatever they want me to do and that's what I'm here for, for them.

Sub-theme 1: Remembering their father

   Five fathers recalled memories of their father. The following phrases give description to this sub-theme of fatherhood.

Sam remembers his dad. He states,

   I always felt lucky to be alive. I think it comes from my dad. He was in the Korean War and had horrible experiences but he was the kind of happy and cheery guy who woke up singing every day and was just happy to be here. I remembered, I eventually understood that perspective and felt the same way, just to feel happy and lucky to be alive. So with that mentality, and now this happens but I’ve lived a good life and up until that point I’ve been able to have a family and enjoy my life.

Shawn also remembered his father who died when he was 23. He states “My son can’t grow up without me. My dad died at a time I thought was early, when I was 23, but this is way earlier. This would be unacceptable. So I got to fight on.”
Charlie remembered his father. He remembered him working hard to provide for his family and giving them a comfortable life but because of his father’s busy work schedule he was not able to spend as much quality time with his father as he would have liked. He does not want to repeat the same with his son.

My dad was always the breadwinner, and he worked very hard, he was always working. He was a butcher and worked seven days a week. I used to joke with everybody and say that my dad and I didn’t have our first father-son kind of thing until I was twelve years old. He took me to a soccer game. He’s still my idol, the person I look up to most in the world and I love him dearly. I always say if I’m ten percent of the man he is, I’ve succeeded in life and as beautiful the memories that I have with him are, sometimes I wish we had spent more time together.

Dave also spoke of his father. He states “my pops is taking it (cancer diagnosis) hard, it’s the first time I’ve seen him this upset.” Then he remembers a fond memory of when he was a child and spending time with his father. He recalls, “Like my Pops did with me. We used to go driving in the car, and he’d take me everywhere that he would go, and I was like his sidekick.”

Antonio remembers having a difficult relationship with his father when he was young but that improved when he got older. Unfortunately for him, his father died of a massive heart attack before they had the chance to become close and build that father-son relationship. He wished his dad was still alive. He recalls,

My father died young of a massive heart attack three days after my 17th birthday. I didn't have the best relationship with my father because I was intimidated by him when I was growing up, he was very strict. We had started becoming closer a year and a half before he got sick and when he died I was devastated…It took me 15 years to get over my dad's death. I wish I had my father here to be able to talk to him. I was just getting close to him.

Antonio’s estranged relationship with his father made him realize he did not want to have the same relationship with his children. He states, “It made me realize when I had my first child, when I had my daughters that I am going to tell them everyday how much I
love them and up to this day I still do. I had promised myself that I wasn’t going to have that kind of relationship with my children.”

**Theme 5: Maintaining Normalcy**

Being forced to face a terminal disease when death is imminent can turn any one’s life into turmoil. Being a father and wanting to live for and protect your children adds even greater stress and makes the situation even more tumultuous. After receiving a cancer diagnosis, a person’s life will never be the same. It will never be normal again. There are too many cancer-related challenges and obstacles that are frequent reminders.

These fathers yearn for and long to maintain a normal life for themselves as well as their children, to just forget for a second that they are dealing with this terminal disease, but too frequently they are reminded that this isn’t the case. Eight fathers talked of maintaining normalcy related to their lives or their children’s lives. The following phrases give a description to this theme.

**Sam** remembers when he learned he had cancer. It was a challenging time for him because he did not feel like himself, he did not feel normal. He tried to live a normal life by continuing to work and maintain a routine. He recalls,

The first month (after diagnosis) was horrible but then, when I was able to come in and start chemotherapy, I felt that I will be all right, like things were turning around and that we were finally doing something. I was sort of settling into the routine and realized that I can sort of feel like a normal person again. That first month I didn’t feel very normal…I felt like it put my life on pause for a month, like everything was weird and I didn’t feel like myself at all. I should say, I felt like a numb version of myself, like a feeling of oh my gosh, nobody knows I have cancer and I was trying to be normal and go to work and do everything I needed to do on a daily basis. I didn’t want to seem or feel like a weak person or anything different but then I started to feel better and realized I was back to my normal self…That was a good routine and you can feel positive that you’re doing something. I always remembered feeling amazing about finally doing something.

Then he recalls trying to maintain normalcy with his children. He recalls,
I wasn’t physically affected in anyway and they (children) didn’t see much change in me, there’s not much difference now. I don’t know how much they think about it in the course of their every day but we (my wife and I) don’t bring it up anymore…I like that the kids don’t treat me differently, I mean, I don’t think I look or act or do anything differently but I like that it doesn’t come up too much. We haven’t been able to ignore it but at least there hasn’t been any drastic changes.

Joe also strives to maintain normalcy for him and his children. He hates talking about having cancer and does not want to be treated differently because of it. He states,

I will be with my family, my brothers and sisters, and the subject won't even come up, which I prefer. I said when I got diagnosed with diabetes last week, that god gave me that to take my mind off cancer, you know. I don’t really like talking about having cancer, especially to the kids, I don't want to make it a major subject.

When it comes to his children, though they are aware that he has cancer, he wants to maintain a normal life for them. They continue with activities and with life as normal but as a father he finds it challenging. He states,

It is difficult to be with them all the time…I’ve changed a little bit. I lost a lot of weight and it's noticeable that I’m not feeling too good but um, you know but they've been very good. I play soccer with them so they know I can still play, you know, I am still in relatively good shape...I think it's better this way that they think, you know, I'm indestructible maybe or that I am healthy rather than being sick, rather than think of me as sick.

Dean talks about how disrupting dealing with a cancer diagnosis has been. He states,

“You have no idea. No idea. It goes through every aspect, every aspect of your life. You know? It just changes everything. So, it’s been rough.” He wants to maintain normalcy but has a challenging time doing so. He is, however, happy that his oldest child, his six-year-old son doesn’t treat him differently. He states, “my oldest son...he knows that I’m sick, but he doesn’t treat me like I’m sick, and I try not to act like some troll.”
He also talks about needing a break from coming to the cancer center for frequent doctor visits and chemotherapy. He just wants a break from it all, to feel normal again, to forget. He states,

When I go to the doctor’s office it’s a constant reminder, like a slap in the face because he’s an oncologist so all the patients there got some type of cancer and a lot of them don't look too good, they are very sick. Sometimes it’s better, like I said, if I’m home, I’m good for a while. I don’t have to visually encounter stuff like that, it definitely helps my psyche…I say to myself, I may look better but I am just as sick as all these people and it puts it, it brings it right up to your face. Now, when you’re home, you are not always thinking about you’re sick. You are doing other things…Once you are in the doctor’s office and you’re waiting to see the doctor and you’re seeing the people that are going to get treatment, it’s like boom, it’s right in your face again. Like I said, if you’re not thinking about it, you’re good. You know if I’m home, I’m with my kid and I’m not thinking of being sick. It’s just nice to have a break from that environment.

**Jose** didn’t elaborate much on maintaining normalcy, but it was an important factor for him as well. He and his family engage in many activities to keep their minds of his cancer. He states,

(We play) a lot of video games, and with my wife we just watch TV together and talk about the day or talk about random stuff. It’s a thing where we try to get our minds off of everything…We try to get our minds of everything but when you’re playing a video game, I start to dwell on it again. I don’t concentrate on the game sometimes. I start thinking about the cancer.

**Charlie** has a challenging time maintaining his normalcy as well. He states,

It does get a little overbearing at times. Especially when I try to live a regular life and try to forget that I have cancer, it comes back and slaps me in the face, and says, “Hey remember you can’t do that, you can’t do this.” It’s not the same energy that I had before and I think that’s one of the biggest hindrance.

At the time of this interview, he was actively receiving chemotherapy and talked about how this has also affected his level of normalcy and being able to function normally. He states,

What is the technical term for that chemo brain thing? It’s valid because I tend to lose my thoughts very easily and not be able to focus. I wasn’t like that in the
past. I lose focus and it bothers me, it bothers me to a point because it reminds me of what I have, that I have cancer and I hate it…I am tired of every week having to do chemo. Just not being myself or not being able to focus.

His norm has changed since his diagnosis. He states,

Normal is a very loose term for me now…I have to remember that. That normal is not what I knew it was. Normal is different, it is completely different. What’s going on now is my new norm. Once I’m finished with this, I’ll have another normal.

Rob also tries to maintain normalcy for him and his boys, and though he has come to term with his cancer, he tries not to dwell on it. He states,

We try to keep our minds off cancer…Cancer is cancer, and since there is no cure, you always got to be concerned, but it's not like, from what I understand it seems like I'm somewhat fortunate because I see people who are much worse. So since I have it, I just have to try not to make a big deal (about it).

Antonio talked about resuming certain activities he enjoyed before his diagnosis and since recovering from his surgery but he is not back to his normal routine. He states, “No, not normal because I was like a horse before I got sick. I could go all day on two hours of sleep and not get tired. I am not back to that right now but maybe one day.”

Woody’s primary focus on maintaining normalcy is for the sake of his children. He has decided that he has no intentions of ever letting them know about his diagnosis. He states,

I don’t tell them (children) anything so they don’t know, they won’t know. I’ll probably take this with me, and I won't say anything about it…I want to keep their home like a complete home…a complete home just for them.

Apart from his children, he also wants to maintain normalcy for himself and doesn’t want any of his distant family or friends to know about his cancer. He remembers losing weight before his diagnosis, and that was a major issue for him. He recalled,

I never wanted people to know, I don’t want them ever to guess. If I do have it (cancer) well, I'm going to be around, and you're never going to know. But you could see there was something wrong, people, who know me, they knew something was wrong. They would ask me, hey, what is that? And I said, no,
man, I'm on a diet, if had to go in for surgery, I would make up anything to throw them off…when I was thin I didn’t go to the house to visit them (children). I told them I didn’t feel well.

In another attempt to maintain normalcy, he states “I don’t want to think about it. The less I know about it, the less I think about it, the less stress I have, the less of everything. So I don’t think about it too much at all.”

**Theme 6: Finding Strength and Support**

Eight fathers spoke of strength and support. Some spoke of finding and receiving strength and support from different sources such as within themselves, family, friends, and religion, while others gave strength and support to those around them. Receiving a cancer diagnosis is a major stressor and finding strength and receiving and giving support is a major coping mechanism. The following phrases give description to this theme.

**Joe** at the time of diagnosis had to find strength within himself. He had to be strong and control his emotions when he was around his children. He did not want them to see him crying. He states, “I tried to hang on for the kids by controlling my emotions in front of them. The first early days, I did not want to be crying in front of them, I think I had cried enough.” He also felt like his children were strong as well. He recalls, “It still hasn’t hit them that I have this cancer, you know. I think they are still staying strong and I still have to keep my emotions under check and not cry in front of them. It’s been hard.”

Joe received a lot of social support from his wife and sons, especially the older one. Since learning about his diagnosis, his wife instills in them to look after him as much as they can. He states, “She gets them all psyched up to, you know, clean up after me or whatever I was going through, she was preparing them for this.”
He also recalls about the last time they were at the water park. He felt supported by his sons. They were concerned about his well-being.

They have never really asked me about cancer but they have asked me, an inordinate amount of time how I am now especially with the diabetes…We were at the park and I was not feeling well. We had a great time but they could see I wasn’t participating in a lot of things and they kept asking if I was ok. They know I am sick you know, and they kept asking me how am I.

**Shawn** was a father that spent the majority of his days from diagnosis in the hospital. He was frequently admitted for months at a time, and he had to find creative ways to cope, find strength and support. One of the ways he did this was by drawing. He and his son drew pictures of superheroes for each other. He states “during the drawings and things like that, I think it was critical for me cause it gave me, um, you know, it gave me some scheduling and that sort of thing.” He also found strength and support when his son, other family and friends visited. “He (his son) came to visit yesterday and last week also. He was up here in the room…my mother just left. Friends come by. Sure, yeah. It helps the day go by.”

**Jose** is fighting a tough battle. He was very sick at the time of this interview. His older children, his two sons are aware of his diagnosis and they are finding ways to be strong as they deal with the situation. He says,

> Being a dad and going through this, I try to be as strong as I can. I put on a face like I’m smiling every day, which is not a fake smile, it’s a genuine smile…They (his two sons) put on a strong front too. If I show them that I’m strong, then they won’t feel scared about it.

He stated that he finds strength and support to cope with his situation from his family and writing. He also finds joy and comfort in his three year old daughter. He exclaimed,

> My family...and writing poetry, that’s my thing. Lyrics, I’m a hip hop artist…I don’t have a deal or anything like that but I do rap and do let it out like that…I love hip-hop so much, that’s something that I listen to every day. That’s
something also that, that’s one of the number one things I use to cope...video games are a silver lining...Nothing against my boys, I love them with all my heart, but it is my three year old girl. It’s my daughter man, that’s daddy’s girl.

Charlie first and foremost found strength in God. He states “the man upstairs blessed us and...in all honesty he is my strength.” He also reports that since being diagnosed, it has brought him back to God. He states,

It’s rekindled me to my beliefs...It’s rekindled this faith in me. I’m a strong believer, if he gave it to me, it’s for a reason. If he gave it to me is because I can deal with it. So then I got to deal with it.

He then turns to his wife and family for support. They seem to be a close-knit family, and they stand by his side and help him in whatever way they possibly can. He states,

I have a great support system. Not so much only my wife but her parents too...Her parents are great. I get along with them very, very well. I call them mom and dad...My wife and her family and my family are very tight-knit so they’re a great support system. My parents, luckily I still have both, they’re always calling me, they’re always coming to visit us. When I do have to come in for chemo and the days after, my mom is the one that takes care of him (son)...Then I have my two sisters; my older sister and my younger sister, Ina and Shana (pseudonyms) respectively. They’re great. They’re the ones that keep life going. I’m very close to my sisters...Everybody tells me how strong I am, and I never noticed until now because honestly I’m glad to have this disease instead of any of my siblings because I would not be able to deal with it the way I’m dealing now...When I feel weak, I just tend to go to my family. They make everything right to be honest with you.

Charlie tries to stay optimistic for his family, but there are times when he breaks down, and when that happens, he cries to his wife. She is his rock and mainstay. He explains,

I kind of try to stay as positive as I can but when I break down usually, it’s only to my wife. She’s always the one that I cry to. My family thinks that I am strong, they’re always saying you’re so strong, you’re always so positive and I tell them I don’t have a choice, I have to be strong, I have to be positive but it’s always up to a certain point. Sometimes I just need to recharge, when reality hits, when it’s just too much, I turn to my wife, she’s the one that’s there for me...Life is too important, my son is too important. I have to do this but when it gets to be too much I break down, just like any other human being. She is my best friend and I feel un-judged by her. Without her I wouldn’t be able to do this. She’s my rock, she really is.
Dave finds strength and support from his child. Since being diagnosed with stage IV pancreatic cancer and being told he has only six months to live, he finds love, joy, and comfort from his son. He states and repeats how supportive his son has been, “he’s been really supportive of me...he’s patient, he’s really supportive...he’s there. He’s just being supportive and being really patient.” He elaborated on this and stated “he hugs me every now and then and, all the time actually. He’s always hugging me out of the blue, and he just enjoys being with his dad...he loves hugging, and he’s a real affectionate kid.” He also receives support from his family. He states “different family members are calling in and wishing me well and stuff. It hasn’t been easy at all. I’m torn down inside.”

On another note, Dave is highly concerned for his son’s future and well-being as it relates to who will support his son when he dies. He wants to create a support system for his son and has a great idea to create a social support group for fathers with cancer and their children. He stated,

I had mentioned before for people in my similar situation, even if just fathers and sons can get together and collaborate, talk about things that are going on in our lives and how to deal with the similar problems we’re having and how to build a better life or just let the kids have fun together and talk about their problems. Like I said, they’re going to have something in common and the meeting will create some kind of bond because they know their fathers are going through a similar situation. The kids will eventually grow up and once we are gone, it could be like a high school reunion knowing they grew up having this similar battle in common, you know.

His goal is also to introduce his son to other family members, so when he dies, he can find comfort and support in his family. He states, “My other thing is to introduce him to more of his family members that he hasn’t met yet. I need him to know that he’s not alone and that they love him very much.”
Rob’s main source of support comes from his children, and as he puts it, his son is more concerned about him and his situation than he is. He states “my 10-year-old worries about it more than me. He always has something like, dad did you take your medicine?” While he does not receive support or help from his biological family, he does have some support from his church family. He states,

I was the last of our family group, and when I was born they were all gone, and they wouldn't be here because I was not born here, and they would have been too old because I'm 60. I have a lot of brothers and sisters spiritually in the congregation.

He has a family member of his ex-wife who helps him with his boys especially on days when he has his doctor and chemotherapy appointments. He states,

Their mother’s cousin is willing to give whatever help they can. So when I have to do anything, she doesn't mind keeping them and getting them to school for me…She usually calls me to find out when I have my doctor’s appointment to see what she can do, she or her mother, to see how they can help…I appreciate the help that they give me now because I need it with the boys.

Antonio seems to have a large support system. Shortly after being diagnosed he went for surgery, and the love and support he received was beautiful. He recalls,

My sister Rosie (pseudonym) came, my elder sister, my nephews and my nieces. They were with my wife and my daughter...My friend who's an ordained minister came to see me with his wife and kid. They prayed for me. One of my good friends Jose (pseudonym) came to see me. My cousin Julio (a pseudonym) and my aunt whom I don't talk too much surprised me that she showed up. My nephews, I practically raised them all, so they’re really close to me, they text me especially the one that’s in the military, he calls me every night. I'm not going to say they're texting, calling or visiting every day but if I need to talk to them I can call them, and they are glad to talk to me.

He found strength and comfort in his mother as well. While he did not tell her right away that he had stage IV cancer or surgery due to her frail condition and health, he still reached out to her and asked her to pray to God for strength. In his moment of weakness, he prayed for strength.
I was crying that Sunday night talking to my mother, she didn’t know I was in the hospital with cancer. She just thought I had pneumonia. She is very religious and we prayed together, I was praying and I started to cry. I said mom, I know you think there’s something wrong with me, can you just pray to God to give me strength.

His bond with his daughters is evident, and they care about his well-being and recovery.

He remembers after his surgery, while he was in the recovery room, his surgeon snuck his younger daughter into the room and when he was discharged from the hospital, she gave him her favorite stuffed animal and never left his side. He recalls,

When I opened my eyes, and I saw her mother and her standing over me, I started crying, and she said, my wife said, why are you crying? The doctor said everything’s going to be fine, and my little one says, you know what, those are tears of joy mom. Daddy’s fine. Those are tears of joy and she’s, just like that she melted me, you know, and I gave her a hug...My daughter gave me her elephant, Mr. Snuffleupagus, who’s been sleeping with me ever since. So, my daughter slept with me for, my 11-year-old, for almost six, seven months. She slept with me, didn't want to leave my sight and she took care of me. She’s the one that really, how can I explain it? She gives me, more comfort.

Antonio did not tell his older daughter that he was diagnosed with cancer. However when she found out, she was a great source of strength for him. He had a tough time initially accepting his diagnosis but in a moment with his older daughter, she gave him a pep talk that encouraged him and gave him a renewed strength to continue this fight. He remembers this conversation and recalls,

She told me, dad, you know something, you always say why you? She said why not you? She said why can't you be the first person to beat this and show people that it could be done, that you can do it...it made me feel like my Superman wings came back, like my cape came back like you know what, why not me, she's right, why not me?

Antonio is not working so he spends a lot of time at home. He’s since noticed how much attention and support he receives from his daughters. He proudly states,

She’s (younger daughter) really attentive to me, she’s always been that way but I guess since I'm home more, I see it more. It's always Daddy, are you okay, and
when my oldest comes home from school, the first thing she says is, Daddy are you all right, how are you feeling, you know and they've always been that way.

**Woody** is a young father of four children recently diagnosed with stage IV renal cell carcinoma. With his diagnosis, he has reached out to God and prayed for strength and has been dealing with his situation well. He recalls when he learned of his diagnosis,

> The news didn’t break me, it didn’t. So, it's, you know, the whole point is just trying to fight through this. Hopefully, I'm strong enough to get through it and just keep on moving forward, that's it. It didn’t hit me right away.

He is preparing himself mentally for the worse but still hopeful for the best. He states, “Hoping the disease doesn’t get the best of me. You know, right now I'm strong, and I'm young, and I'm fighting it but who’s to say, you know? Even the strong fall.”

Since his diagnosis, he has renewed his relationship with God, and he prays for strength. He states,

> I’ve prayed for strength and for some reason I'm able to deal with it. I’m able to cope and it’s all right, you know and even if I get bad news it doesn’t upset me, so you know I’ve been able to deal with everything...I've seen others when I come here (cancer center) and you can tell they're going through a tough time and sometimes I think whether it’s because of my age, or because of prayer or whatever it is, but I am thankful that I am strong enough to deal with this and have accepted my condition. You know, I don’t think other people would take this news, the same news the same way that I have taken it, you know, this will break anyone. I’m just glad I have the inner strength to get by and to not put so much thought into it and just enjoy life.

With his inner strength and faith in God, he continues to fight and be strong. He states “I’m not going to let it get the best of me, nor mentally, nor in no shape or form it’s going to get the best of me.”

**Theme 7: Dealing with Challenges**

Being diagnosed with a terminal illness such as cancer can cause one to face many challenges on a daily basis but facing these challenges while being a parent of
underage children can exacerbate or create further challenges. The fathers in this study are already challenged by the fears of this life-threatening disease and the reality of death but other challenges arise as well. These include coming to terms with the initial cancer diagnosis, the emotional aspects whether it was related to the father or child, the complications and side effects of cancer and its associated treatments as well as maintaining open communication between them and their children. The following phrases will give description to the challenges faced by the ten fathers in this study.

Sam was shocked when he received his diagnosis. It was a big surprise for him and his wife. He recalls, “I guess it was a surprise for everybody and it’s not like I got this diagnosis, processed it and came to terms with it quickly...I never, never expected to be diagnosed with cancer.”

Another challenge for Sam was talking about his diagnosis and having open communication with his two older children. He had a friend ask him if he told the children about his cancer, to which he remembered thinking that it was going to be a really difficult thing to do. He recalls, “and that was, for whatever reason, that was the hardest question to answer because I knew what that meant.” Sam did speak to his older children, though he was unsure of how much they would understand but he wanted them to be aware of what’s happening and to feel free to ask any questions or express any concerns. He recalls,

I told my two older kids before I really fully knew what was happening. I said you're going to hear us talking a bit, I got diagnosed with cancer but we don’t know the stage of it just yet and I actually didn’t think that they would really grasped it, you know. I couldn’t tell how much they actually knew about cancer but my oldest daughter had recently read a book on cancer and she had a lot of questions. She asked a lot of pertinent questions and I was very surprised.
Sam felt that having this interaction and maintaining open communication with his older children was a good way to keep the situation under control.

I have open communication with them. I didn’t want there to be some secret that all of a sudden somehow they found out that their dad has cancer. So I just wanted to tell them because I also wanted to control it too…I said um, you know, anytime you wish to ask me anything, just ask me. Ask whatever is on your mind.

At the time of the interview, Sam was actively receiving chemotherapy, and the side effects were interfering with the time he spent with his children. He stated,

The only part I regret is that I get my treatments on Thursday and Friday, so over the weekend I feel like I’m in a haze and I cannot enjoy my time with them, then I’m back to work on Monday. I can’t stand the feeling of not being well when I’m around them so I’ve been thinking about switching my chemo days to Monday and Tuesday so by the time Thursday or Friday is here I will be feeling better and can enjoy the weekends with them.

**Joe’s** main challenge was talking to his children about his diagnosis and controlling his emotions when he was around them. When he found out about his diagnosis, he had his wife tell them the news. He couldn’t bring himself to do it. He recalls, “My wife told them right away about it. I couldn’t bring myself to do it. I was too emotional and felt like I had cried enough. It was best that she told them anyways, at least for me it was, it was what I wanted.” Then he remembered the next time he saw them and how emotional he was. He states,

I had a few tears and it was hard you know, it was a hard weekend to get through…I tried to hang on for the kids and control my emotions a bit, you know, in front of them, especially during the first early days, I did not want to be crying in front of them, I had cried enough…I just keep my emotions under check and it was hard in the beginning. Several times I had to turn away because I had tears.

Another challenge Joe faced due to his pancreatic neuro-endocrine tumor is his diagnosis of diabetes, which is a cancer-related complication. He stated, “They warned me that one of the outcomes of this cancer is having diabetes.” This was a big challenge for him
because he did not feel well when he was spending time with and taking care of his children. He was also hospitalized as a result. He recalled, “Especially with the diabetes...We were at the park and I was not feeling well. We had a great time but they could see I wasn't participating in a lot of things and they kept asking if I was ok.” As a complication to diabetes, Joe lost weight and his children noticed and were concerned about their father’s health and well-being. He stated, “I've just had to sit back here since being diagnosed with diabetes last week and I think they are more, I’ve lost a lot of weight and I think they noticed and they’re asking more questions about how are you.”

Dean’s primary challenge stemmed from the stressors of his job. He feels that if he did not have to work, he would be able to overcome his cancer, though there is currently no cure for multiple myeloma. He states,

> Waking up, just waking up at 6:30, throwing your clothes on and taking care of business is a lot different than jumping out of bed at 5:00 in the morning, jumping in the shower. To me, not for nothing but the grind is what wears a lot of people out. It’s just the grind, and I say this all the time, if I didn’t have to work every day, I would be able to fight this much better.

He describes his work environment. “It's a very volatile environment that at any moment it could just explode. That puts a little stress on you.”

Shawn’s journey since his diagnosis was, for the most part, spent on the inside of a medical facility that began on the initial day he was diagnosed. He was very sick, and this was the primary challenge for him because it kept him away from his son. He was his main caretaker. He recalls,

> About eight months ago, back in April when I first was diagnosed, it was devastating to me, and I didn’t know when I’d see my son again. So, I was diagnosed and put in the hospital. No one can tell me how long I’d be in there for the first day and, you know, I was the main caregiver at the time for our four year old son…That devastated me because all I could think about was how am I going to see my son right now…He would always ask me, Daddy, when are you coming
home? I’d say, I don’t know, hopefully soon. So it was very difficult back then...I was there for two months.

Shortly after this, he was discharged home with severe fatigue. This was another challenge but he got stronger. Cancer-related side effects and symptoms as well as frequent hospital admissions were amongst Shawn’s main challenges. He recalls,

I was home for a month, and then my son and I connected well but I started out feeling really tired, but I got much stronger when I was home. Then I went back into the hospital for another two months...my first admittance was in April, mid-April to mid-May, my second admittance was mid-July to mid-August there were just a lot of steps involved here...I’ve been in the hospital, oh gosh, at this point, you know over 150 days or something like that, more.

He was then discharged home again, but fatigue remained a challenge for him. “I was just home for a couple of weeks, I was exhausted and I wasn’t able to chase him around too much.” Shawn was then admitted to the hospital again for a bone marrow transplant which, if successful could have extended his life for a few months, maybe even a few years. For this procedure he was in the hospital for four-six weeks because the recovery period is long. He was discharged home, and in less than two weeks was re-admitted again for relapse. His transplant was unsuccessful and his cancer had returned. During this admission, he developed some adverse effects.

This particular admittance is different from all the others. The others were all some schedule for me, whether it be a chemo or a bone marrow transplant but this round right now, I was only supposed to be there for a few days but it’s now been over two weeks. I just had chemo, and they’re still trying to figure out what the next steps are going to be because my transplant wasn’t entirely successful. It’s a problem. So, I think things are still being figured out, and while it’s been happening, you know, I got pneumonia, and I got a rash, and I got a fever, so, I’ve been stuck here.

His future was uncertain, and he wasn’t sure about anything. He states, “It’s all very hazy right now because I don’t know what’s next regarding my treatment. Usually, I know what’s next but I don’t know right now. They’re figuring things out.” As a father,
Shawn faced many challenges but the hardest part of it all was being away from his son.

He stated,

The hardest part has been, um, well really being away from my son for months at a time, and I never thought I would ever be able to be away from him for months. So, that’s been really hard and I guess the up-and-down nature of the whole thing. You get good news one day, bad news the next and much worse news the next. It’s been emotionally tough to have to go through all this.

Jose faced many challenges since being diagnosed with stage IV renal cell carcinoma.

His challenges focused on dealing with the initial diagnosis, failing different chemotherapies, frequent hospital admissions for surgery or pain management, side effects and or other complications, among others. When Jose was asked about his experiences as a father with cancer, his first response was how stressful it was dealing with the disease and worrying about his children. He states, “Every day is a struggle because I think about them at the end of the day at most times.”

Initially, he was misdiagnosed. He presented with hematuria, was diagnosed with a urinary tract infection and placed on antibiotics. His symptom did not resolve, and a scan of the abdomen and pelvis revealed a mass. A biopsy confirmed the diagnosis and he needed emergency surgery. He recalls, “Right away I had to have emergency surgery to remove the kidney but they also found out it had spread to my lower lungs.”

This was the beginning of his battle with cancer.

The first chemotherapy I was on was called Votrient. He (oncologist) said it was working at first but then the cancer started growing very slowly. Then he had to change it. So the second time, he changed it to another chemotherapy which was also a pill. This one seemed like it was working but another scan after three months showed that it wasn’t and that it was growing slowly again. So then he gave me chemotherapy through the veins and I’m going to tell you right now it didn’t work, even the first trial was a waste of time and in the mean time I developed an obstruction of the intestines and needed emergency surgery again... They took care of that and then I got out of the hospital, went home and the recovery time was about three to four months. Then I went then back to see
my doctor where he told me options about chemo again. He ordered another scan and everything was still steady. Everything was still the same even when I was in the hospital, so cool. I’m on another chemotherapy pill form. That chemotherapy made me feel good, it didn’t mess around with me. It felt like everything was working out but then I started getting swollen feet…It was tingling, I couldn’t walk, I couldn’t do anything, so they admitted me to the hospital again. I told them that I couldn’t even lift my arm, I had arm problems. I couldn’t lift the left arm all the way up, it would stop right in the middle. Every time I tried to lift it above my head, I couldn’t and it was just an excruciating pain on my shoulder…when they did a scan of my arm, they found crystals in my bones. These little crystals had to do with cancer and they had to take them out right away. I got surgery for that, it was uncomfortable, it was not good.

After recovering from his surgeries, he was placed on chemotherapy again and developed more side effects and complications. He recalls,

Then he put me on another chemotherapy…This pill was horrible. I started having symptoms within the week. I was coughing up blood, I was coughing really bad. It would hurt my chest, and was very nauseous. I couldn’t, I’ll eat something and nausea would come and last until the next day but I’ll never vomit. It was also making me feel very short of breath. It was also giving me this back pain, it was excruciating, it was a very sharp pain.

Shortly after this, he was re-admitted again but this time, it was for pain management.

I got admitted to the hospital again because of severe back pain. The back pain was not going away and for a whole week they were just monitoring me. They gave me painkillers and were trying to find the right regimen. They thought they did and they sent me home but when I got home, the pain started again. Then I had a whole week of going through this pain and the stress. I kept thinking it was going to go away but it didn’t. The next week I felt very nauseous. I felt tired, I couldn’t get up. It was just a thing where it was really bad. I had even taken a week’s break off the chemo and then got back on it. When I got back on the chemo, things started happening again. I couldn’t walk far distances, I was always short of breath and everything like that…I started feeling a sharp pain in my side. It was not as it was before where I could handle it. This pain was like oh my God I couldn’t even sit down.

He was re-admitted again for pain management.

Jose took a while to come to terms with his diagnosis but apart from all that it was just a very exhausting and stressful time for him. He states,
I was negligent towards it...I was in big denial. To tell you the truth it was like just the exhaustion, always going to the hospital, always have to follow up, always have to do this and do that...It’s a thing where you’re putting in so much and you feel like you’re doing so little. That’s what it is. It’s a roller coaster ride.

Jose had his fiancé inform their children about his diagnosis. He was going for surgery, and she didn’t want him crying in front of the children. He recalled,

I didn’t tell them, their mother did because I was going through the surgery. She felt like she had to tell them before I did because she didn’t want me breaking down in front of them. She was preparing me. She told them and they broke down crying because they knew what it was. When I talked to them about it after I recovered, I told them that what I have is very serious.

Jose and his children maintained open communication regarding his cancer from this point on. He remembered dealing with the side effects. This was very challenging for him. He recalls,

The toughest part is just dealing the side effects...The nausea, the weakness, the feeling like I don’t want to do anything. Before this I was so energized, I was going everywhere...It’s just very hard when you’re dealing with the side effects. These chemos give you so many different side effects it’s not even funny. Nothing’s funny about it.

As a complication of cancer, he had lost a significant amount of weight. He stated, “I used to weigh 230 pounds, now I weigh 125...It was just so weird to see me get skinner and skinnier every month.” It was evident that Jose has a special bond with his three year old daughter but due to his weight loss, fatigue, pain and other side effects he has not been able to play and interact with her as he would like. He sadly stated,

It’s a shame I can’t pick her up anymore...It hurts when she jumps on me so I got to tell her you can’t do that to daddy, it hurts. She gets it, she goes sorry daddy...I can’t pick her up anymore because of my back and everything, it sucks.

Charlie’s challenges focused mainly being diagnosed with a rare cancer, being a new father of an eight-month-old baby, receiving chemotherapy and dealing with the side effects. His current situation has him emotionally drained. He states,
It’s been incredibly challenging being a first-time father...on chemo days and chemo weeks, it gets a little rough. The side effects, the nausea, the fatigue, it all comes to light especially when you have a couple of months old baby that needs your attention and sometimes does not want to go to sleep...to get diagnosed with cancer, with urachal cancer that’s incredibly rare and have it spread to the lungs is even worse, you know. The hits, the blows just kept coming. I needed to get a partial cystectomy and all these things were just earth shattering for anyone, especially for me because I never thought there would be anything like that. I never thought I would have cancer even more so at this young age...the fatigue, it gets to me. Even then, what is the technical term for that chemo brain thing? It’s valid because I tend to lose my thoughts very easily and not be able to focus...My attention is very different now. I can’t concentrate on things like reading a paper or a book. I lose focus quickly now...Just being tired of every week having to do chemo. I break down, and I curse this damn chemo and this damn cancer, you just get tired…I’m tired, and I guess that’s what sums it up the best. I’m just sick of it.

He is the main caretaker for his son, and these challenges affect this in a negative way.

He states,

I speak to my friends that have kids. Having a kid is hard. It’s very demanding if you’re going to be that attentive and involved father. Balancing that with having cancer and not feeling well, and having to deal with this new schedule of having a new little human being that I have to worry about, it’s all about him now. I don’t get sick cards with my son. Now, I have this other thing, this other big elephant in the room which is cancer and chemo and side effects and not feeling well and then all that, so it’s been difficult because of that...It is incredibly hard but if I sit back and dwell on it I’m not going anywhere. I just got to keep moving, I’ve got to keep going. It’s not easy having cancer. I just feel like it’s two opposites that I have been dealt with at the same time, dealing with cancer and dealing with a brand new baby boy. I guess I am up for the challenge because I’m still going through it but it’s been a whirlwind of emotions.

**Dave**, like all the other fathers, dealt with the same challenges. Being diagnosed with stage IV pancreatic cancer and given only six months to live, has been a very emotional endeavour for him. He has had a difficult time adapting and accepting his diagnosis. He says,

Because of the different emotions and things I’m going through, I’ve been lashing out at people. Sometimes they’re being helpful but I just get frustrated very easily and quickly. I’ve been short tempered a lot lately, so you know, it hasn’t been easy for me...I’m trying to take one day at a time but it’s just been a whole plethora of emotions. I’m concerned about my mom and my parents and stuff and
especially my father. It’s the first time I’ve seen him upset like that you know, and it’s just a lot of emotions, and it’s hard to explain. It’s hard to put words to it...It's been an emotional rollercoaster, up and down.

Another major challenge for Dave has been the complications and side effects as it relates to the cancer and chemotherapy. He states,

It’s hard for me, these injections because I don’t have the real energy to go out and do what I want to do with my kid the way I want to…the pain, just dealing with the pain you know, and everything, I was on different pain meds. They had me on various opiates which didn’t agree with me at all. I don’t like that stuff so I just went cold turkey, and I’ve been trying holistic medicine and stuff. I mean, what can I lose at this point...dealing with the cancer, just the fight with this thing. The pains, the weaknesses and I can’t do things that I used to do because I’m weak. I’m a serious mountain biker. I like to mountain bike and I just haven’t had the energy to do it like I want to. I’m frustrated...Even my hair’s been falling out…Nutrition wise, I haven’t been having much of an appetite, so that’s another big concern of mine. I don’t want to end up being one of those statistics where I die from malnutrition instead of the cancer. The chemo and stuff has destroyed my appetite, I don’t want to eat anything...It’s challenging though. You want to do what you think is best for you, but then how do you even know what the best option is, that would be beneficial. Do I go holistic? Do I go Western medicine? How do I find the balance or anything like that?

Early on, Dave decided to maintain open communication with his son regarding his cancer though, his initial thought was to withhold this information. He states,

For us, it started over the phone, I spoke with him. His mom spoke to him and told him I was sick and at that time I was still hopeful that they can do something to help me. I told him that I was sick with cancer and hopefully the doctors can fix me and he was really hopeful for that...It made me feel like a weight was let off on my shoulders because in the beginning, I was thinking how to hide this from him and not let him know until the very end but then I changed my mind. I decided to tell him and hopefully he can rock through this ordeal with me and understand what’s going on...My son, since he’s my one and only, I try not to hide anything from him, and I try to keep him abreast of everything that’s going on.

Then he remembered when he learned of his diagnosis. This has been an ongoing challenge as he tries to accept it. He recalls,

So many things are flowing through my head right now, it’s hard to even put words to it. It’s like when I first found out October 21st that I had cancer, I wasn’t knowledgeable about it and when the doctor told me over the phone, I was
lost...He told me I had pancreatic cancer, and at that point, I didn’t know what to think. I thought I was going to drop dead on the street right then and there you know, or any moment…It’s like, what can I say? I mean, I’m still lost. It’s got me so lost to the point where I haven’t even touched on my religion. It’s like I’m still dabbling in religion, and I still can’t grasp this thing….It hasn’t been easy at all. I’m torn down inside. I’m still at a point where I’m confused. I don’t even know which religion, because I grew up Baptist and then converted to Islam and um, you know I haven’t even been in touch with it. I’ve been praying but it’s been off and on, even here in the month of Ramadan, it’s been hard… I would like to fast you know, and be cleansed of all my sins so to speak. Religion is a concern…I’m more lost for words because I’m still confused…I still can’t believe it. I mean I smoked cigarettes here and there coming up, smoke pot coming up and I stayed active. I was always mountain biking or either hiking or doing something active. For me to get this cancer is like wow. I mean how does a healthy person get this cancer? And then I’m trying to trace back in my mind what I was around.

Rob has a single challenge and that revolved around having no close family or friends he can entrust his children’s well-being and spiritual development to should he die. He states,

Since we don’t have a cure for multiple myeloma, it's nothing that makes me fearful, however, what it has affected is that since I'm a single parent with two boys, 7 and 10, it does make me feel a little apprehension every night when I go to sleep because I don't know if I will wake up…I do have a few family members, but they do not measure up to what I want the boys to have. My parents and grandparents, well I was the last of our family group, and when I was born they were all gone, and they wouldn't be here because I was not born here, and they would have been too old, because I'm 60. I have a lot of brothers and sisters spiritually in the congregation, but when you get to my age, you don't want to burden people with your responsibility if you don't necessarily have to.

He is hopeful that one day he will meet someone, a suitable partner and remarry.

I told them that one of the solutions is getting married again and they didn’t have a problem with that. I explained to them my situation. I said, I'm sick, and you never know what might happen. If something happens to dad and he doesn’t wake up, I want you to be able to stay with somebody that will love you as much as I do or, at least close to it…I may be gone in my situation and then my boys will be left out in the open.

Antonio faced similar challenges as the other participants. From dealing with the initial diagnosis, the emotional aspect, complications of cancer as well as having that open
communication with his children. He recalls when he received the initial diagnosis and how emotional it was.

It’s been full of emotions. It’s been humbling, scary, frustrating, it’s been eye-opening, it’s ah, I can choose plenty of words. It’s been scary. I feel a whole lot better since my diagnosis because at that time, I was scared and angry. I was angry because I've never abused drugs, I’m not a smoker, I’m not a drinker...I just, at times I look for somebody to blame, and I search for something to blame, and I just realize that there’s, well I realized there’s nobody to blame.

Antonio had a challenging time accepting and coming to terms with this diagnosis. He felt that this cancer was God’s way of punishing him and it caused him to search for God. He recalled,

If you would've seen me months ago when I first got diagnosed, four, five months after, I was in a deep depression, constantly crying, always asking why me...I tried to rationalize things, and sometimes I think that when I caught cancer that this was God's way of punishing me...All of a sudden I got sick, and it humbled me, it scared me when I found out that I had cancer and I searched out for God.

Before the diagnosis, he recalled being sick for months but was misdiagnosed and treated for pneumonia. His symptoms did not resolve and his condition worsened. He states,

Before my diagnosis, I was sick but continued working for six to eight months. I was sick every day. I thought I had an ulcer. I went to the doctor, he thought it was pneumonia and he gave me antibiotics but then I started having a lot of pain to my lungs and my back. To make a long story short, they found I had fluid in my lung and they had to punch a hole and remove 30 pounds of fluid. There was more but I started to cough involuntarily and they had to stop. Then they found that I had cancer but they didn’t tell me right away...I realized I was in an oncologist office, and she told me there is a 98 percent chance you have cancer, lung cancer. I said lung cancer? I’m not a smoker...I was angry.

Another challenge he faced was having extensive thoracic surgery and a long recovery process. “The surgery was 6 hours long.” As part of the recovery process, he began doing physical therapy and recalls “I started doing the physical therapy. I was scared because I didn’t know, you know, it was hard. The first couple of months were hard for me.”

Shortly after being discharged from the hospital he began chemotherapy. “I started
chemo right away. It was a hard first couple of months getting through the chemo. They were giving it to me every three weeks.”

Initially, he kept his diagnosis hidden from his older daughter but when she found out they maintained open communication regarding his condition and progress. He recalls, “My oldest daughter didn’t know. She was in college. I didn’t want her to know...I didn't want to tell her. I found out I had cancer the day of her birthday, and she was in school.”

Since she has learned of his diagnosis and has been an excellent source of support for her father.

Woody’s main challenges revolved around his initial symptoms and losing weight as a complication of his cancer. He recalls,

I had a cough and it didn’t feel right, you know, it wasn’t normal, it was messed up, it was outrageous, and I knew there was something wrong. I could tell. I’m used to, I’m a guy that used to walk six miles to work...when I see that my endurance isn’t the same or my stamina isn’t the same, I knew there’s something wrong you know, especially when I eat well, drink water all the time, don’t drink soda, you know, I take care of myself pretty well to know when something is wrong. I’m no doctor but I would know, and when I start to see that I’m not doing things normally like I normally do, I walk three miles to work, and it only takes me 45 minutes, 50 minutes, so, it’s as though I’m concentrating on exercising. Now when the walk is taking me an hour and a half, and you’re not stopping to look at anything, and you’re out of breath, you know there’s something wrong and that’s how I started to notice that something was wrong.

He also recalls losing weight.

I started losing weight. Like I weighed 180 something you know, I was very muscular, all of a sudden, I’m beginning to see muscle is going, I’m getting thin, my face was you know, I’m like, oh, this isn’t good. It was, that’s what got me the most. That’s what hit me the most.

Interpretive Statement

The interpretive statement that arose from this research brought to a close that through the lived experience of fathers with advanced cancer, an overall description of a
father’s unconditional and eternal love for his children becomes apparent when faced with death. This is the sixth and final step in the van Manen (1990) research process. The context of the study is balanced by considering the parts as well as the whole. This included reflection by stepping back from the data (parts) in an attempt to grasp the entirety of the phenomenon that is being researched. Through this reflection, I was able to evaluate the wholeness of the research findings in context as it related to the parts, and to see how the parts contributed to the whole (van Manen, 1990). The narrative descriptions and meaning units from each father’s interview provided the data that supported the emerging themes that captured the lifeworld that each father described. These themes were related to the parts of the research and the wholeness of the phenomenon that came together to culminate the interpretive statement about the experiences of fathers with advanced cancer. Through the application of van Manen’s (1990), 6 step process of conducting interviews, reflecting on themes, writing, rewriting and interpreting, the lived experience of these ten fathers with advanced cancer was described and understood.

The interpretive statement was formed from the analysis of the data and portrays the essence of the phenomenon being studied. The combination of the seven themes that arose from this research captured the totality of the lived experience of these fathers. These fathers showed an unconditional and eternal love for their children when faced with death. Receiving a cancer diagnosis made death a reality and forced these fathers to look at their mortality knowing they will be leaving their children, the ones they love the most. As a result and based on the findings of this study, the interpretive statement is as follows: *A father’s unconditional and eternal love for his children when faced with death will do anything to “live longer” to continue to love and care for his children, continue*
to work as much as they can to give them “financial security” now and after their death, spend whatever time he has left “making memories” so his children will remember him fondly, be a good father and take his “fatherhood” role seriously, “maintain normalcy” and not let his cancer or dying status disrupt life, find and give “strength and support” to and from his children and in the end, facing and “dealing with challenges” that a cancer diagnosis brings. A dying father will do this and more, to continue to be a good, loving and present father and would do it all over again if it meant they would be able to live longer and spend more time loving their children.

This statement reflects the connection of all seven themes and the overall meaning derived from them. It depicts the essence of the lived experience of fathers with advanced cancer when death is imminent. The phenomenon of a father’s unconditional and eternal love when facing death encompasses sacrifice, protection, and caring for his children and revolves around a painful transition and departure from this world. A dying father’s love, like Tim who fought to live in the face of death for his children, and like each father in this research, is an unconditional love, an eternal love, a true love, an honest love. Their love for their children knows no limit and has no boundaries. The fathers in this research study are being forced to deal with dying and leaving their children. This is not as easy task and time as a factor is limited. It is however evident through their interviews that they are doing the best with whatever time they have left and like the poem by Gabriel Garcia Marquez, I know they will express their unconditional and eternal love for their children until their final breath.

“If I knew that today is the last time that I am going to see you asleep, I would hug you with all my strength and I would pray to the Lord to let me be the guardian angel of your soul.”
If I knew that these are the last moments to see you, I would say “I love you.”

There is always tomorrow, and life gives us another opportunity to do things right, but in case I am wrong, and today is all that is left to me, I would love to tell you how much I love you & that I will never forget you.” (Marquez, n.d.).

Summary

Chapter V described the findings of the study that included the recruitment process, the research setting, the participants’ experiences and the themes that emerged. Also discussed were the thematic analysis, rigor and it ended with the interpretive statement that described the essence of the lived experience of fathers with advanced cancer. van Manen’s (1990), phenomenological 6 step methodology was applied to the data analysis process and described in detail. Chapter VI will present and expand on the reflection of the findings.
CHAPTER VI: REFLECTION OF FINDINGS

Introduction

The purpose of this qualitative study was to describe and understand the lived experience of fathers with advanced cancer when death is imminent. Ten fathers participated and seven themes were uncovered and identified through the data analysis of the interviews and reflection of the findings. They include: live longer, financial security, making memories, fatherhood, maintaining normalcy, finding strength and support, and dealing with challenges. This chapter will expand and reflect on these themes and will provide supporting statements from the current literature to synthesize the data. The themes will be described and reflected through the lens of a nursing model or theory chosen to guide this study. The limitations of the study, the implications for nursing practice and recommendations will also be discussed.

Synthesis of the Data and Literature

A review of the literature from the fields of anthropology, medicine, nursing, psychology and sociology was conducted and yielded no previous studies that addressed the lived experience of fathers with advanced cancer. The majority of the existing research focused on mothers with cancer and some focused on parents where a small to moderate number of participants were fathers. Only one study by Elmberger, Bolund and Lutzen (2002) was found that looked solely at fathers. Their study focused on men with cancer who attempted to master their self-image as a man and a parent. This reflects a definite lack of research on fathers thereby creating a great need for ongoing research in this patient population and speaks volumes to the importance of this phenomenological study. This research will help narrow this gap in the literature as well as to assist and
educate nurses and other health care professionals in supporting and providing gender-specific care to fathers with advanced cancer as we understand what is important for them at this critical point in their lives.

**Theme 1: Live longer**

The theme “live longer” was divided into three subthemes. The first subtheme of the fathers in their hope to live longer was to comply and adhere to the prescribed surgical and medical treatment plans as depicted by their oncologist. Several fathers were grateful for the advances in medicine that has kept them alive up until this point and are hopeful for future advances that will keep them alive even longer. For many of them, they hoped to live as long as possible to see their children grow to an age where they are independent and can care for themselves. Some were even hopeful for a cure. This coincides with a study by Rashi, Wittman, Tsimicalis and Loiselle (2015) that looked at parents who were balancing cancer and parental demands while raising minor children. The parents were hopeful that their cancer was only “temporary” and some described it as a “good cancer” with good outcomes. The fathers’ primary concern in this study was to stay alive till their child or children are of the age where they can take care of themselves and not be dependent on their parents (Rashi et al. 2015). Elmberger, et al. (2002) also found that the fathers in their study wanted to live as long as possible to see their children grow up. They were diagnosed with cancer at a time where their children were in young and sensitive development stages. The fathers saw their presence as being greatly needed and that to die now, would be to die at the wrong time. They also expressed a sense of hope and luck regarding having a treatable cancer and other factors for favorable outcomes (Elmberger et al. 2002).
The second subtheme to living longer focused on the fathers wanting to either start or resume a healthier lifestyle by making improvements in their diets and daily physical activity levels. They hoped for desired outcomes, in that being healthier would assist them in their fight to overcome cancer. Some fathers even talked about resting and decreasing stress levels as a way to promote health.

Engaging in a healthier lifestyle after a cancer diagnosis is documented in the literature. In a study that investigated whether adults changed their lifestyle behaviors after a cancer diagnosis reported that approximately 46 percent of the sample made dietary improvements (reduce fat and red meat, increased fiber) but only 15.7 percent reported exercising more (Blanchard, Denniston, Baker, Ainsworth, Courneya, Hann, et al. 2003). In another study that looked at 356 adult cancer patients, two-thirds of the participants reported making at least one lifestyle behavior change. Approximately forty percent made dietary improvements (increasing fruits and vegetables and decreasing fat), twenty percent began exercising and fifty percent began taking dietary a supplement. The majority of these participants reported that the changes improved their health and well-being (Patterson, Neuhouser, Hederson, Schwartz, Standish & Bowen, 2003). A positive body image was related to good physical fitness, endurance and the ability to cope with daily routines and stressors. This was reported in a study that looked at men with cancer (Vaartio, Kiviniemi & Suominen, 2003). Some of the fathers in this study even spoke of resting and decreasing stress levels as part of being healthy. Physical capacity was related to physical integrity and relaxation (Vaartio, et al. 2003).

The third subtheme to live longer is to reach certain milestones either in the fathers’ lives or their children’s lives. The thought of dying and leaving their children
at such a young age and developmental stage was unthinkable and they weren’t ready. One father spoke of wanting to become a grandfather and one simply spoke of taking his son on opening night to see the new “Star Wars movie in December, 2015. Several fathers in this study talked about being alive to see their child or children graduate college, get married and have a family. A study by Semple and McCaughan (2013) confirms this. The parents’ main priority was concern for their children and they expressed fear of dying and not being around to witness important milestones in their child’s life such as educational achievements, birthdays and weddings. Another study by Semple and McCance (2010) looked at the experience of parents with head and neck cancer when caring for young children and showed that in light of facing death, parents feared missing important milestones such as their children’s wedding day, birthdays and graduations. Sheehan and Draucker (2011) reported that the parents in their study were aware of the ramifications of their advanced cancer. They knew their time with their children was limited and all participants expressed great concern and grief over the loss of future time together. They spoke of dying and missing their children’s prom, graduations, weddings and meeting and getting to know their grandchildren.

**Theme 2: Financial security**

Many fathers in this study reported financial issues. Several were related to being unemployed in some capacity because they resigned or were on disability and finances were not readily available. However, some fathers that were currently employed also reported financial issues. This shows that financial security is a real concern regardless of employment status. Several fathers were the primary caretaker so there was no additional expense to hire a baby sitter.
Financial security for the fathers in this study revolved around current everyday and future issues. Current issues focused on being able to pay their bills, and just having financial freedom to live a comfortable lifestyle and provide whatever they can for themselves and their children. Semple and McCance (2010) concurs. Participants in their study reported that their family’s financial situation dictated when they returned to work since having a lower household income created a struggle to pay their bills on time with less money to spend on miscellaneous things for their children. Future financial issues mainly revolved around their children’s education. This was reported in Sheehan and Draucker (2011) where several parents reported discussing college plans with their adolescents and made financial arrangements for them prior to dying.

The literature reports several economical issues. Financial obligations, such as bills prevented spouses from taking time off from work to look after the children when the other spouse has cancer (Rashi, et al. 2015). In a study looking at men with prostate cancer and how its treatment affected their bodies, roles and masculinity, one of the primary concerns of the men was how would they continue to provide financially for their wives and children (Chapple & Ziebland, 2002). In a qualitative study looking at gender and spousal support after being diagnosed with colorectal cancer that was conducted by Emslie, Browne, MacLeod, Rozmovits, Mitchell and Ziebland (2009), it was found that half of the men in the study talked about sorting their finances so that their wives would have access to it while they were ill or their families would be provided for if they died. Ernst, Gotze, Krauel, Romer, Bergelt, Flechtner et al. (2013) looked at gender differences and psychological distress in cancer patients with underage children. They found that for male patients, being employed significantly lowered the risk for an
anxiety disorder and they were less likely to feel depressed. It was also found that the men who were significantly affected by anxiety were fathers of underage children (Ernst et al. 2013). Fathers reported having control of their personal finances was a great plan in preparation for their death and planning for their surviving family (Elmberger, et al. 2002).

**Theme 3: Making memories**

Being diagnosed with advanced cancer caused each father in this study to realize that their time with their children is limited. As a result, many of them focused on fun activities and spending more quality time with their children. Several of the fathers were the main caretaker either on a daily basis or for a period of time and this allowed them to spend extra time with their children. The fathers on disability feared going back to work because they know their time is limited and would hate any missed opportunity to spend as much time as they can with their children. Several fathers in this study focused on photos and other memorabilia and some simply had quiet moments observing and listening to their children.

Time away from work gave parents a chance to spend extra time with their children (Rashi, et al. 2015; Semple & McCance, 2010). Some studies found that the fathers’ roles transitioned from a successful working man to a man being at home with his children. This time with their children created a closeness and awareness of their children’s everyday life. Since being home, they have been able to spend more time together as a family and do activities with the children such as cooking, homework and traveling (Elmberger et al. 2002; Semple & McCance, 2010). The negative experience of having cancer was balanced with positive ones that reflected a shift in family values and
priorities (Semple & McCance, 2010). They also reported that several participants, after
treatment had an “internal struggle” because they now live with uncertainty and fear of
recurrence and with their increased appreciation for life, want to be able to spend more
time with their children (Semple & McCance, 2010). Parents tried to spend more time
with their children and listened to them more (Houldin & Lewis, 2006). This was also
noted in Sheehan and Draucker (2010). Some parents wrote letters to their children to be
opened in the future, some took photos and made videos as tributes so their children can
have and remember them after they die.

Theme 4: Fatherhood

The theme of fatherhood encompassed the participants enjoying being a father,
being able to love, care for and nurture their children. All ten fathers in this study
embraced fatherhood and they were all present and active fathers in their child’s or
children’s lives. Many took on several of the following roles: caretaker, educator,
nurturer, supporter, counselor, provider, protector, and friend and to a lesser degree,
disciplinarian. They were all proud of their children and made them a priority while
battling cancer. Some of the fathers were concerned for their children’s future and well-
being (who will take care of them) when they die. This coincides with Helseth and
Ulfsaet (2005). The needs and well-being of the children were the parents’ first priority.
The parents wanted to protect their children’s interests by being available, by including
the children and allowing them to live life as usual. According to Elmberger, et al.
(2002), several fathers, since they were not working took on a more involved fathering
role and began attending school meetings and helping their children with homework.
They have also found some positive implications to having cancer, in that they see their
lives in a new light and were able to evaluate what’s important and valuable in life (Elmberger, et al. 2002). This was also a finding in this study. Receiving a cancer diagnosis allowed many of the fathers to put their lives in perspective, to prioritize and focus on what’s important.

**Theme 5: Maintaining normalcy**

Being forced to face a terminal illness like cancer will create havoc in anyone’s life and elicit many questions and concerns. The same holds true especially for parents or in this case, fathers with underage children. Concerns and uncertainties are reflected in questions such as, “How much longer do I have to live?” “How much more time will I have to spend with my children?” or “Will they be taken care of and supported emotionally and financially when I am gone?” With all these concerns and the daily struggle with cancer, one’s perception of normalcy is permanently altered. The fathers in this study, many from the time of diagnosis and dealing with the complications, side effects and facing death have struggled to maintain normalcy for themselves as well as for their children. Their lives will never be the same. This coincides with Vaartio, et al. (2003), who reported that the men in their study knew that they were not and will never be the same person they were, either physically or psychologically, prior to their diagnosis.

Several fathers in this study tried to maintain normalcy when their physical appearance was compromised such as through weight or hair loss. Some tried to ignore the cancer and not make it a topic of discussion. Others tried to remain pre-occupied, not think or dwell on it or avoided coming to the cancer center because seeing all the sick patients reminded them that they have cancer too. Some had their normalcy altered due to
the complications or side effects from cancer and its treatments. They all tried to live a normal daily life for themselves and their children by engaging in regular activities such as working or participating in fun activities with their children.

Several studies reported the need for parents to minimize change and allow their children to enjoy a normal everyday life by maintaining their daily routines (ex. school, activities, play, meals, bed time) and special occasions such as a vacation (Helseth & Ulfsaet, 2005; Kennedy & Lloyd-Williams, 2009; Rashi, et al. 2015). Preserving children’s activities during one parent’s chemotherapy meant that the spouse had to take extra daily responsibilities despite continuing to work outside the home (Rashi, et al. 2015). In Semple and McCance (2010), some parents, despite their best efforts to minimize disruption in their lives and their family members’ lives, found that the change in normalcy was inevitable, especially when the side effects of their treatments became more apparent. Some parents were motivated to maintain normalcy by re-establishing a routine. This enabled them to regain an element of control which often led to an improved sense of psychological well-being (Semple & McCance, 2010). In a study looking at patients newly diagnosed with advanced colorectal cancer, many of the participants described how their lives have been disrupted. Many struggled with maintaining normalcy with symptoms such as incontinence, insomnia and altered sexuality. Their daily routine was also affected by symptoms and some felt like they were standing still with their lives and future on hold, (Houldin & Lewis, 2006). One father talked about maintaining normalcy for himself where he wanted to stay out of the hospital. He reported in Elmberger et al. (2002), that the hospital environment is depressing and passive and he has a strong desire to stay home as much as possible.
because there’s a deep feeling of healing at home compared to the hospital. He can’t bear to see so many terminally ill people and not be overcome by a strong feeling of loneliness (Elmberger, et al. 2002).

**Theme 6: Finding strength and support**

Finding strength and support to deal and cope with a life-altering and life-threatening disease such as cancer is a daily and ongoing battle. Many of the fathers in this study were the recipients of strength and support that they found either within themselves or from their partner, children, other family members or friends, or in their religion and faith. Another father found strength in writing. This coincides with the literature where participants identified friends, their wife or children, parents or grandparents, employers or colleagues or their spirituality or church as primary sources of emotional and psychological support (Elmberger, et al. 2002; Houldin & Lewis, 2006; Rashi, et al. 2015; Semple & McCance, 2010; Vaartio, et al. 2003). Rashi, et al. (2015), found that several fathers with cancer felt that their illness affected their spouse more than themselves and made a link between their gender and showed strength for their family. Emslie, et al. (2009) found that many participants were extremely positive about the support they received from their partners during their illness and that it strengthened their relationship. The men described the support from their wives as emotional strength, dependability and lack of fuss (Emslie, et al. 2009).

Many of the fathers in this study also reciprocated strength and support to their family members and friends. They felt that if they portrayed strength, they will be a source of support and strength to those around them. This coincides with findings from Helseth and Ulfsaet (2005). They reported that cancer patients received support but they
also gave a great deal of support to those around them, they were strong for their friends, family and children. Rashi, et al. (2015) also found the parents described the need to keep the morale high, exemplify strength and positivity and encourage their children to remain hopeful about the outcome. They reassured their family that everything would be OK (Rashi, et al. 2015).

**Theme 7: Dealing with challenges**

The challenges faced when diagnosed with cancer are innumerable and unfathomable, especially when facing death and leaving your children behind as is evident by the fathers in this research. This was a repeated concern throughout the interviews but other challenges arose as well. These included maintaining open communication with their children, the emotional aspects and the complications and side effects that resulted from the cancer and its treatments.

Several fathers struggled with the challenge to inform their child or children of their cancer diagnosis and keep them abreast of their prognosis and treatments. Many shared this information in greater detail with their older children and some opted to tell their younger child that they are sick, withholding details. Having and maintaining this open communication in relation to the amount of information that was shared, depended heavily on their children’s developmental stages and their ability to fully understand and comprehend what was happening. Rashi, et al. (2015), found that several participants chose to communicate certain types of cancer information to their young children by simplifying or withholding information about their diagnosis, prognosis and treatment, but that parents of adolescents were more open, addressed key issues, and dispelled myths. Helseth and Ulfsaet (2005) also found that parents understood the importance of
sharing realistic and sufficient information regarding their cancer to their children. Some questioned whether their children understood what they were told. The parents in Semple and McCaughan (2013), varied in how and how much information they gave their children regarding their cancer diagnosis. Some immediately informed their children as a way to gain control over the situation while some delayed sharing the news because their children were too young or because they were not emotionally ready (Semple & McCaughan, 2013). The fathers in Elmberger, et al. (2002) opted to give minimal information to their children and rarely used the word cancer. Semple and McCance (2010) also reported that some parents were overwhelmed with the thought of speaking to their children about their cancer. Some were still coping and coming to terms with their emotions while others wanted to protect their children from the hurt and negative emotions. When the decision was made to inform the children, the parents were very cautious about the timing and the amount of information they shared. They decided to be open, honest and tell the truth and communicated the information based on the ages and developmental stages of their children (Semple & McCance, 2010). Parents struggled with telling their children about their cancer, particularly the younger ones. There were concerns that too many details could negatively affect them, (Houldin & Lewis, 2006). Some fathers in this study could not bear to be the one to share the news with their children so they had their partner or wife do it. This coincides with findings by Rashi, et al. (2015), where the strategy to selectively disclose cancer information was also directed to spouses or other family members.

Receiving a cancer diagnosis is a major psychological event and elicits many emotions. This is another challenged faced by the fathers in this study. Being a father
with underage children, having an advanced cancer that is incurable and facing death is even a more emotional feat that these fathers are forced to face. Many of the fathers in this study were shocked, fearful, angry, frustrated, and confused by the initial diagnosis. Vaartio, et al. (2003) found that depression, fear of the unknown and the need to keep the situation under control were among some of the emotions the men in their study faced. They also experienced anxiety, a feeling of suspicion and uncertainty during their doctor visits. The fathers in Elmberger, et al. (2002) expressed hope, doubt, satisfaction and anxiety, uncertainty and humility in living in fear of having a relapse. The drastic changes that these fathers are experiencing were found to be exhausting emotional experiences with many losses and difficulties in showing their sadness (Elmberger, et al. 2002). Some parents in Semple and McCance (2010) also reported fear should the cancer recur. They described it as “living under a cloud of uncertainty” and some felt uncertain about making long-term plans for their families.

Several fathers in this study, due to being emotional were not able to be the one that discussed their diagnosis with their children. Rashi, et al. (2015), found that some parents tried to hide some of their sad emotions and that their time to “feel” and “breakdown” occurred when their children were sleeping. Many of them cried, but as time went by and they began treatment and recovered from their surgery, they became more accepting of their diagnosis. Many of them became hopeful and were motivated to keep moving forward. Another emotional aspect, as reported in Semple and McCance (2010), was related to several parents being separated from their children because of hospital stays. Several parents in their study experienced this and it was dictated by their emotional readiness to handle the situation. Some parents saw this in a positive light to
offer emotional support to their child or children and to be motivated to continue
treatment, (Semple & McCance, 2010). Frequent hospitalization with time spent away
from their children was also reported as a challenge for several fathers in this study.

Apart from dealing with the psychological and emotional challenges of cancer,
the physical challenges add to an already complicated situation. All the fathers in this
study experienced physical challenges on some level. These were related to the cancer
itself and or its associated treatments. Physical cancer-related challenges that were
reported includes but were not limited to the progression of disease and failure of the
chemotherapy to eradicate, shrink or stabilize the cancer, frequent hospital admissions for
pain management, surgeries and other complications like fevers, pneumonia, weight loss
and becoming cachectic. One participant was diagnosed with diabetes as a complication
to his pancreatic neuro-endocrine cancer. Prior to receiving a cancer diagnosis, several
participants in this study exhibited symptoms such as a cough or weight loss and sought
medical attention but were misdiagnosed, thereby delaying their much needed treatment.
Vaartio, et al. (2003) described suspicion of cancer in terms of physical changes such as
weight loss.

Physical challenges that were related to cancer treatments focused on the side
effects. These side effects included but were not limited to fatigue and weakness, nausea
and vomiting, shortness of breath, “chemo brain” and the inability to focus or
concentrate, anorexia and alopecia. Rashi, et al. (2015), found that several participants
did not want their spouse, children or parents to see the visible signs of their illness (pain,
weakness, hair loss, wounds) and some had to push through physical barriers (fatigue,
risk for infection) that affected regular activities with their children and their own
discomfort to put their children first. Chapple and Ziebland (2002) found that some men had to give up the things they enjoyed because of the side effects from prostate cancer treatment (fatigue and pain). Vaartio, et al. (2003) reported that the men in their study, while receiving chemotherapy experienced weight loss, alopecia, nausea, anorexia and fatigue. The fathers in Elmberger, et al. (2002) reported frequent negative feelings during the chemotherapy such as nausea, a bad taste in the mouth, body pain, vomiting, a pale appearance, hair loss, retarded nail growth and dysfunctional skin production. Incontinence, weight loss or gain, flatus, sexual dysfunction, changes in sleep patterns, and severe fatigue were reported in Houldin and Lewis (2006). Fatigue and other physical factors related to advanced cancer such as pain and paralysis limited the amount of time spent and restricted shared activities among the parents and their children in Sheehan and Draucker (2011).

**Thematic statement Using a Nursing Model**

This descriptive phenomenological research study was conducted to describe and understand the lived experience of fathers with advanced cancer. The concluding finding that arose from this research study and brought to a close the lived experience of fathers with advanced cancer, revealed an overall descriptive emotion of love for their children when forced to face death. This love for their children can therefore be looked upon as a compensatory adaptation mediator as they continue to find meaning in life as a father. The Roy Adaptation Model (2009) served as a nursing model that guided the process to understand the father as an adaptive system, functioning for a purposeful cause.

The Roy Adaptation Model (RAM) (Roy & Andrews, 1991; Roy, 2009) view individuals as bio-psychosocial holistic beings that are capable of adapting
effectively to changes in their environment (Roy & Andrews, 1991). Therefore, the capability of the individual to adapt is based on choice. Individuals, such as fathers with advanced cancer are open systems that are in constant interaction with their environment. According to Roy (2009), they receive input known as stimuli that elicits a response. Stimuli, such as advanced cancer and dying induces stress and these fathers find ways to cope, adapt and maintain their integrity. As previously discussed in chapter two, the RAM has four adaptive modes in which coping processes can be observed. These modes are the physiological, the self-concept, the role function, and the interdependence and it is the goal of nursing to promote adaptation in these four modes.

The selected phenomenon of the lived experiences of these dying fathers with advanced cancer can be viewed as focal stimuli. Therefore, the research question of this phenomenological research is focused on the father’s experience as the adaptive system in relation to focal stimuli and its stressors (advanced cancer, dying and leaving their children). The philosophical assumptions underlying the RAM (2009) focus on people's mutuality with others, in other words, individuals share in creative power, behave purposefully, strive to maintain integrity and realize the need for relationship (Roy, 2009). It is this need for relationship, that the fathers in this study must share in creative power, behave purposely and maintain integrity with their children when death is imminent.

Roy (2009) identifies input as stimuli, which can be focal, contextual, or residual and states that adaptation occurs when the stimuli can be treated and the individual reaches his/ her adaptive level which is the ability to respond positively, meditatively or negatively in a situation. Since the goal of nursing is to promote adaptation, the nurse
assumes a facilitating position in providing the help needed to promote adaptation. The regulator and cognator subsystems control the processes of adaptation that operate on the stimuli. The regulator subsystem is characterized by the physiological responses, coping and adaptation, which occurs automatically in response to a stressor. The cognator subsystem responds through four cognitive-emotive channels that includes perceptual and information processing, learning, judgment and emotion that relieves anxiety and promote effective adaptation.

Adaptation can then be seen as a process where individuals use awareness and choice as integrating human and environmental factors. Analyzing the findings of this study, I realize that the dying fathers, through deeper questioning, awareness, and consciousness, attempt to adapt when they realize that being a parent is the greatest gift of presence, peace and love. Self-examination of the father’s feelings and knowledge about death and dying provide them with a mechanism for effective adaptation.

Following the RAM (2009), adaptation for the dying fathers becomes living their lives to the fullest and spending whatever time they have left with their children before their body is overcome by cancer and dies. Not only to live today by the memories of yesterday, but to live today to the fullest, enjoying every possible moment with their children expressing their unconditional and eternal love as they realize and accept their transition out of this world. A dying father’s love can therefore be looked upon as a compensatory adaptation mediator where his love for his children can be seen as a process to use awareness and choice to integrate human and environmental factors and be able to confront death as they transcend to eternal life. The father’s feelings and knowledge about his illness illustrated by the essential themes that emerged through data
analysis became the behaviors that allowed adaptation to death. The process of developing and over-expressing their unconditional and eternal love for their children knowing their time is limited, concurs with the RAM (2009). It states that adaptation creates an optimal integration of human and environmental stimuli resulting in optimal well-being. A well-being that focused on their children.

The essence of a father’s unconditional and eternal love as depicted and reflected in the seven emergent themes from this research study demonstrates that the fathers utilized and focused on their love for their children as a way to accept their imminent death and transcendence. It is important for the nurse to understand and recognize that the internal mediator is an inner love, which allows the fathers to discover who they are through deep questioning of that which is beyond human life. When all the preconceptions of what they are have been stripped away and the truth surfaces, the reality that remained is a legacy of unconditional and eternal love for their children. The legacy of each father’s love became an imperative and conscious awareness that their children will always have to cherish and remember long after their father dies.

Results from this research depicts that when a father learns that he has a life-threatening diagnosis like advanced cancer, it ignites a desire within him to constantly express his love for his children since time is limited. When a father is faced with death, he will go to great lengths to live longer, to provide financial security now and after death, to spend whatever time he has left with his children making memories, to be a good father and take his fatherhood role seriously, to maintain normalcy and not let his cancer or dying status disrupt his children’s life, to give strength and support to his children and in the end, dealing with challenges that a cancer diagnosis brings. These are
the ways in which the ten fathers in this study showed love to their children. A dying father will come full circle and do all this and so much more, if it meant they would be able to live longer and have more time on this earth to love their children.
Figure 1: Thematic Model of a Dying Father’s Love
Limitations of the study

The limitations of this study must be considered. This study looked at the lived experience of only ten fathers with advanced cancer when death is imminent. This small but purposeful sample may not be an accurate representation of the views of all fathers with advanced cancer and therefore cannot be generalized to this specific patient population. Since this is a qualitative study, randomization to an interventional and control group was not done. Its generalizability is therefore further limited and its findings may not be applicable to this specific population or others that are similar.

The participants in this study did not reflect a homogenous sample. Though they all resided in a large urban city and sought care in a large metropolitan medical center, there were many differences. Their children were of different ages and developmental stages. The fathers were of different ages, ethnic and socioeconomic backgrounds amongst other factors. They also represented a variety of cancer diagnoses and were at different stages in their journey. For example, a father may have been initially diagnosed with advanced cancer and is at the beginning of treatment where other treatment options are available if the current one fails, while some may have not been initially diagnosed with advanced cancer but unfortunately progressed and are toward the end of their treatment options. These factors may have had some influence in each father’s experience and may not reflect this specific patient population or others that are similar.

Implications for Nursing Practice

This research study is the first effort to look at the lived experience of fathers with advanced cancer and is one of two studies that looked solely at fathers with cancer. The experiences, as told by the ten fathers in this study, gave a better understanding of their
experiences as fathers with advanced cancer when death is imminent. The emergent themes and essence derived from their experience gave great insight to what is important for them at this critical point in their lives and can influence nursing education and nursing care. The following are implications for nursing practice that were inspired by this research:

- First and foremost, under graduate and graduate degree nursing curriculum should incorporate more evidenced-based practice for end-of-life care and experience for their students. As it stands, nurses have always been at the forefront of bedside care and caring for the terminally ill and dying patient has long been the job of the nurse. This will increase preparedness in their graduates to provide competent care for such patient populations.

- Health care facilities that care for this patient population and similar ones should foster a supportive environment for their staff and promote educational seminars, conferences, forums, case studies, etc. that will provide ongoing up-to-date and evidence-based information on medical advances and technology in caring for terminally ill populations. This is of importance because staying abreast of such information may assist nurses in being advocates for their patients to assist them to live longer and provide a sense of hope.

- This research brings to light the importance of discussing and preparing for end-of-life issues. A father with an advanced cancer diagnosis should be realistic and begin the process of having advanced care directives in place. Nurses are in an excellent position to initiate this conversation, assess the father’s readiness and intervene accordingly.
A major challenge in this study was how and when to share information regarding the father’s cancer diagnosis with their children of different ages and developmental stages. Oncology nurses should be aware of the potential difficulties, the importance of ongoing assessments and providing appropriate resources and support for fathers especially those with underage children, (Elmberger, et al. 2002; Rashi, et al. 2015; semple & McCaughan, 2013; Vaartio, et al. 2003). Nurses should also refer to other specialties such as social work and psychology when necessary.

The results of this study provided an increased awareness of what is important to these fathers at this point in their lives. In turn, this may allow nurses to better support these fathers in this transition and to strengthen their resources, (Vaartio, et al. 2003). While the fathers in this study found support from various sources, separate from nurses and other healthcare professionals, it still remains nursing’s responsibility to assess their coping mechanisms and support systems and intervene as needed. Nurses can offer timely and empathetic support and information when the patient is ready (Vaartio, et al. 2003). We can foster open relationships and communications with these fathers, letting them know they’re not alone and offer support in whatever way we can.

It’s been documented that the entire family is affected when a parent is diagnosed with cancer. Meeting the needs of the father as well as the other family members may help reduce anxiety, build family confidence, and ultimately improves health outcomes (Maxwell, Stuenkel & Saylor, 2007). Nurses can assess and plan
family-centered interventions accordingly and can influence and assist family members in meeting the needs of these fathers.

- Many fathers expressed financial concerns for their children’s well-being and future. In recent years, several charitable and crowd-funding sites such as GoFundMe has become available. Many higher educational institutions also provide financial aid and scholarships. As a nurse, reminding such fathers of these resources can be beneficial and alleviate some of the financial burden and stress they may have.

**Reflections of the Researcher’s Experience**

Every once in a while you meet a patient who touches your life in a special way and your nurse-patient relationship blossoms into something more beautiful than anticipated. This is what happened to me several years ago when I met Tim. I was touched and influenced by his struggle to live while he was actively dying from multiple myeloma. He had developed severe side effects to his chemotherapy but insisted on receiving it as scheduled in his hope of living longer to be able to spend more time with his children and to watch them grow, to love, live and celebrate life with them. However, several months later he died and lost his battle to cancer, leaving his most prized and loved possessions behind, his two children. His passion and desire to live for his children stirred a concern and curiosity within me that fueled my passion and desire to describe and understand the lived experience of fathers with advanced cancer.

This study has become a labor of love and I am forever humbled and changed that these ten fathers so willingly opened up to me about their struggle with cancer, about their unconditional and eternal love for their children, about their hopes and their fears.
As I sit here and reflect on their journey and how they allowed me to be that instrument, to see through their eyes what this experience has been like for them, I am overwhelmed by emotions. I dedicate this work to them, to their struggle, to their children, to their never ending love. I can only hope that I have done justice to their experience.

It is my hope that their story will be a source of strength and encouragement for other fathers who will go through a similar but unfortunate journey. That this patient population will no longer be neglected in the nursing and oncology literature, that through this research and ongoing research on fathers with cancer, that nursing and other health care professionals will understand and support them through this process. A father’s role and presence in his children’s life is so important and his unconditional and eternal love can never be replaced.

At this point, it breaks my heart to inform you, the reader that several fathers that participated in this research study have died and moved on to the next life leaving their children behind. When the physical body is overcome by cancer and can no longer maintain life, it gives up and succumbs to death. Shawn did not get the opportunity to take his son to see the new Star Wars movie on opening night. Jose will not be able to see his sons graduate from college or dance with his daughter at her wedding. Shortly after his interview, we never saw or heard from Dave again. While we hope that he is alive and doing well, this may not be realistic as his cancer was so advanced and only given six months to live. Though their physical body is no longer with their children, it is my prayer that their spirit will always watch over them and that they never forget the unconditional and eternal love their father gave them. They may never fully understand their father’s struggle but I hope they remember feeling his love. In doing this research, if
I’ve learned one thing about dying and a father’s love, it is this: the difference between grieving, dying and loving, is when you are dying you grieve, but when a father is dying, he loves. And if I were to imagine these dying fathers’ final moments, I can see them saying a similar but simple prayer, Dear God, if you have to take me, if you are calling me home, please take care of them, in your hands I commend my children.

**Recommendations for Further Nursing Research**

My dissertation is the first research study that looked at the lived experience of fathers with advanced cancer where death is imminent. The nursing and oncology literature reflects a paucity of research on this specific patient population. Though, research on fathers has been gaining popularity and interest in recent years, it is needless to say that there is still a tremendous amount of work to be done on fathers. Future research on this population is necessary to assist us in gaining a better understanding of their experience and process and to narrow the gap in the literature.

Qualitative and quantitative research is required to assess how advanced cancer in this patient population affects their different roles as it pertains to their marital status, ethnic, socioeconomic and religious backgrounds, single fathers, fathers with same sex orientation, just to name a few. Longitudinal studies from diagnosis to end of life and qualitative and quantitative studies looking at fathers in hospice and supportive oncology programs that have exhausted treatment options will be also beneficial. Looking at a dying father from the spouse, child’s or a nursing point of view can yield invaluable insight on how each population view the dying father. Ongoing research in fathers with advanced cancer will be monumental in caring for fathers and dispelling myths such as fathers are macho, don’t need social support among other important issues.
Summary

This chapter focused on the reflection of the study findings. Analysis of the data revealed seven themes. These seven themes were compared to and synthesized with the current and established literature. A brief thematic statement was discussed. A thematic model was presented that reflects the findings of the study. The limitations of the study, implications for nursing practice, reflections of the researcher’s experience and recommendations for further nursing research was reviewed and discussed.

Conclusion

The primary goal of this research study was to describe and understand the lived experience of fathers with advanced cancer. Ten fathers participated and utilizing van Manen’s (1990) phenomenological method, seven themes emerged from this study. These themes illuminated the essence of a father’s unconditional and eternal love for his children when faced with death. This essence brought to a close, this study that looked at the lived experience of fathers with advanced cancer.
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