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PERSONAL GROWTH IN COUPLES CARING FOR A CHILD WITH A
LIFE-THREATENING ILLNESS

By

Kimberly Kennedy

B.Sc. (Kin), University of Waterloo, 1996

THESIS

Submitted to the Faculty of Social Work
in partial fulfilment of the requirements for

Master of Social Work

Wilfrid Laurier University

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Abstract

Little is known about the potential for positive outcomes in couples who have a child with a life-threatening illness. The current study was a secondary analysis of demographics and personal growth data of 34 couples actively caring for children with various life-threatening conditions. There were three overarching goals in this research: (a) to examine differences in Posttraumatic Growth Inventory scores (PTGI) of mothers and fathers, (b) to examine the relationship between demographic variables and PTGI scores of mothers and fathers, and (c) to measure level of congruency in couple-dyad scores and test if partners' growth scores are predictive of one another.

Findings showed significant differences between the Total Growth scores of mothers and fathers, with mothers having significantly higher scores. Of all areas examined, interpersonal growth appears to be the most sensitive to demographic factors. A number of significant relationships were found between demographics and scores on the Relating to Others scale of mothers and fathers. Fathers' personal growth was related to age, age of child, time since diagnosis, how well income meets needs, and importance of religion. The growth of mothers was related to community size, how well income meets needs, importance of religion, and diagnostic category of child's condition. Congruency testing showed that couple-dyads were no more likely to report similar degrees of growth than they were to report opposite degrees of growth. However, interpersonal growth and spiritual change scores of one partner were highly predictive of those reported by his or her partner.

Implications for social workers and other professionals to recognize the potential for positive outcomes and factors that may influence personal growth in couples caring for a child with a life-threatening illness are addressed.

Acknowledgments

I would like to begin my acknowledgments with some apologies and a plea for forgiveness from the people closest to me. I apologize to my wonderful friends and family who I have neglected to call or visit periodically over the past two years. I am especially grateful to those who did not remind me that I once swore I would never return to school. My partner, Dave King, also deserves an apology for involuntarily having his living room, dining room, bedroom, and attic turned into what at times resembled a library struck by a tornado. He has not seen the kitchen table in months and his kijiji-time has been drastically cut by my monopolization of our computer. Thank you for your patience and your humour. No one makes me laugh like you do.

It has been an honour and a joy working with my thesis advisor Susan Cadell. I met Susan at a time when I was still considering applying to the Faculty of Social Work. Her passion for research that serves to acknowledge the strengths and resilience of people was inspiring. My discussion with her about the work she was doing with a team exploring pediatric palliative and end-of-life care solidified my decision to pursue my MSW. She has continued to be an inspiration throughout the writing of this thesis.

I would also like to thank my committee members, Rose Steele and Nancy Freymond. Thank you for the time and energy you committed to helping me create this project. David Hemsworth also volunteered his time to provide consultation and answer my numerous questions about statistical analysis. With the support of these people I feel I have become a better researcher. The quality of this project would not have been the same without their attention to detail and valuable insights.

It is funny how life's journey seems to randomly lead us to the places we need to go. Brenda Spiegler hired me for a job that I was under-qualified for because she had confidence in me. (Or, maybe it was the letter I wrote to her saying how wonderful I thought she was.) Her confidence never faltered and this was a motivating factor for me to pursue graduate school. She knew she had no one to blame but herself when I asked for a reference letter. I attribute my

interest in research to my work with Brenda. Through our informal journal club I learned to both appreciate and critique research. She also gave me the opportunity to work on “real-life” research. The first time we gathered to look at our data on neuropsychological outcomes of children treated for leukemia, I had this surge of adrenaline and sense of euphoria. I remember my cheeks being red and talking really fast after that meeting. I think Brenda put her hand on my shoulder to keep me from bouncing down the hall. I was hooked!

I have been fortunate to be surrounded by many strong women in my life who have shown confidence in me and inspired me to pursue my goals. In my mother’s eyes, I could apply to be Prime Minister and at the very least get a second interview. For better or worse, I continue to draw upon my grandmother’s words of wisdom and share them with the adolescent girls I work with, “Never take anyone’s crap.” She never did. In response to my crazy ideas my cousin and best friend, Cindy Jackson, shows her confidence in me in a way that always keeps me grounded – “Shut-up! You are not!” Cindy and her wonderful husband, Wes, have provided me with the greatest motivation of all – Topher, Sweet Emily, and Midgie. I challenge myself in the hope that they will someday be inspired to do the same. I dedicate this thesis to these three very special children as a thank you for their love and the personal growth I have experienced because of having them in my life. I have been blessed.

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Chapter One: Introduction

*“Embrace misery because misery is a great teacher.”
Malcolm Saulis*

With advances in diagnostic procedures and medical care, increasing numbers of children are surviving life-threatening conditions that previously would have taken their lives during the perinatal period or in infancy (Emond & Eaton, 2004). These children often survive into late adolescence or early adulthood. Couples caring for a child with a life-threatening illness (LTI) bear tremendous responsibilities. In addition to the psychological, emotional, spiritual, and physical consequences associated with being a caregiving parent (Cook, 1984; Jones & Neil-Urban, 2003; Kane, Barber, Jordan, Tichenor, & Camp, 2000; Parker, 1996; Steele & Davies, 2006), the dynamics of the family, particularly the marital relationship, may also be challenged (Cook; Davies, Gudmundsdottir, Orloff, Sumner, & Brenner, 2004; Jones & Neil-Urban; Parker; Monterosso, Kristjanson, Aoun, & Phillips, 2007). Couples are continually making decisions regarding medical interventions, which may serve to heighten their ongoing feelings of uncertainty and ambiguity about the future of their child (Cohen, 1995; Jones & Neil-Urban). Families often face financial instability as a consequence of added medical and equipment expenses, child care, travel to and from hospital, and time away from work (Corden, Sloper, & Sainsbury, 2002; Monterosso et al.; Morrod, 2004; Parker).

In addition to the day-to-day stressors of caregiving and fulfilling family obligations, couples may also be overcome with intense emotions such as shock, anger, or guilt that they are not able to protect their child. Guilt may also stem from the sense that they or their partner are somehow responsible for their child’s plight (Canadian Hospice Palliative Care Association & Canadian Network of Palliative Care for Children [CHPCA & CNPCC], 2006). Anticipatory grief often occurs well in advance of the end-of-life phase in association with such losses as the expectations for a normal life when a child has been diagnosed with a condition causing serious physical or cognitive disability (Field & Behrman, 2003). Mothers and fathers, as well as

children, may be overwhelmed and potentially find themselves immobilized by their grief (Cincotta, 2004). Thus, a parent's ability to remain physically and emotionally available to his or her child may be seriously challenged. At the same time, in order to cope with their LTI, and ultimately their death, children require tremendous support from family members. The beliefs that children hold about living with an illness and dying reflect the beliefs and attitudes of their parents (Cincotta).

Because parents play such an integral role in influencing their family's quality of life, it is important to explore and gain an appreciation for the realities of couples caring for a child with a LTI. It is through my experience working with children with cancer, brain tumors, and various degenerative conditions that I have gained tremendous admiration for parents as they strive to maintain balance and promote well-being in the midst of uncertainty. I have worked with many selfless parents who appear to instinctively place their child's needs before their own, often presenting with a strong façade and optimistic demeanor, if for no other reason than to offer a sense of assurance to their impressionable child. Though often surrounded by chaos and ambiguity, these parents seem to have made the decision, consciously or unconsciously, that they will not allow themselves to succumb to despair. Such parents often emit a sense of hope that I find inspiring, if not mystifying. What traits do these mothers and fathers possess that enable them to move forward and persevere while caring for a child whose future is unknown? What are the virtues of a relationship that seem to empower and unite some couples through the stress and grief of a child's diagnosis? To honour the strength, resilience, and commitment of these couples, I have chosen to focus my research on positive aspects of their experience, specifically on perceptions of personal growth.

As a student of social work, I feel that exploring the potential for positive outcomes associated with caregiving and other stressful events is consistent with Saleeby's (2002) strength-based perspective that has been encouraged throughout my training. This approach emphasizes strength and resilience, rather than problems and deficits. Such a perspective has been adopted

increasingly across disciplines by clinicians and researchers who recognize that the medical model orientation, which has traditionally been widely accepted, is insufficient. There has been a growing acknowledgement that in order to achieve a more holistic perspective greater attention needs to be given to positive aspects of the human experience, including investigations into the phenomenon of personal growth (Joseph & Linley, 2008; Park & Helgeson, 2006; Tedeschi & Kilmer, 2005).

Personal growth, as described in greater detail below, refers to the positive changes that individuals experience through a process of meaning making and the reconstruction of beliefs and goals following a crisis (Helgeson, Reynolds, & Tomich, 2006; Hogan & Schmidt, 2002; Joseph & Linley, 2008; Tedeschi & Calhoun, 1996; Tedeschi & Kilmer, 2005). Recent investigations have documented reports of perceived growth in individuals who have experienced such tragic incidences as natural disasters, rape, incest, war and combat, bereavement, and illness (see Helgeson et al. for a complete reference of studies investigating benefit finding and growth up to early 2006). Focusing on growth is not intended to detract from the distress and discomfort that couples caring for a child with a LTI experience. Rather, the process of growth is presented as occurring along with the negative aspects that are traditionally given prominence when considering the outcome of trauma, stress, or grief (Calhoun & Tedeschi, 2006).

In addition to emphasizing the negative aspects of caregiving, much of the research into the experience of parents of children with serious illnesses or disabilities and pediatric palliative care has relied almost exclusively on maternal reporting (Macdonald, Chilibeck, Affleck, Cadell, in press; Ylven, Bjorck-Akesson, & Granlund, 2006). Researchers wishing to provide a complete and balanced understanding of couples' caregiving experiences must not only consider the possibility of positive outcomes, but must broaden their focus to include the voice of fathers.

It is my sense that the experience and opinions of mothers are often privileged within health care settings and by researchers investigating parental functioning in pediatric illness and disability. I believe that this practice unintentionally contributes to the alienation and oppression

of fathers that can occur. Failure to include men in the care of their ill children perpetuates cultural stereotypes that fathers are unwilling or incapable of providing quality care. Since as early as the 19th century, a commonly held perception has been that women and men are naturally suited for certain roles. For generations the male as breadwinner and female as caregiver gender-model has laid the foundation for the family system that continues to be a dominant part of today's western culture (Thompson, 2002). As a result, men who have taken on the role of primary caregiver, for a spouse, elderly parent, or child, are viewed as having crossed over a stereotypical masculine-feminine boundary.

Since the mid-1990s there has been mounting interest within the field of gerontology surrounding the experiences of caregiving men; however, little effort has been made to design gender-relevant interventions to support these male caregivers (Kramer, 2002). A similar movement is afoot in the areas of pediatric illness, grief, and bereavement. Of strong relevance to social workers are the questions of how gender differences may influence patterns of grief and how this knowledge can best be integrated into clinical practice. Doka and Martin (2001) emphasize that the issue of gender differences should not be discussed without acknowledging the wide variations within male and female roles. They present a valid argument that gender patterns be viewed as overlapping, rather than completely separate and distinct. Though researchers tend to highlight difference found between men and women, clinicians should be cognizant of the high degree of commonality that exists between genders.

The focus of my current research was on providing clarification and insight into how gender influences personal growth in mothers and fathers who are together caring for a child with a LTI. This study served to identify differences between reported growth in mothers and fathers, as well as areas of overlap and similarities. Asking questions about growth in couples and factors related to this process adds to the current understanding of the potential for positive outcomes associated with parental caregiving. Promoting a holistic perspective of this experience, and raising awareness of the nature of personal growth, enables social workers and members of the

health care team to be better situated as they strive to support couples throughout the trajectory of a child's illness.

I begin by outlining and defining terms used throughout my thesis. A literature review on pediatric palliative care and parental functioning in the context of childhood illness is presented, followed by an overview of personal growth, and research findings related to gender differences in growth and growth in couples facing a medical crisis. Research methodology is outlined followed by a report of study results. In addition to relevant findings, the discussion section identifies limitations of the current study, thoughts about future considerations, and implications of this research for social workers, health care professionals, and family members involved in the care of children with life-threatening illnesses.

Chapter Two: Terminology and Definitions

The following section outlines terms used throughout this thesis, including terms commonly associated with personal growth and pediatric palliative care. Definitions are intended to clarify terminology selected and to distinguish terms that may be used interchangeably by health care professionals and researchers.

Caregiver and Care

I used information collected through a study entitled *Caregiving Parents of Children with Life-Limiting Illnesses: Beyond Stress and Coping to Growth* (Cadell, Siden, Davies, Steele, Straatman, Hemsworth, & Liben, 2006). As part of the Caregiving Parents Study participants completed a survey that defined a *caregiver* as “a parent or guardian who provides care for a child who has a life-limiting illness and is not paid to do so”. The term *care* was described as anything parents or guardians did because their child has life-limiting illness. Some examples include: household chores that take more time (e.g., extra laundry or preparing special meals); direct care of the child, such as bathing, feeding, skin care, administering medications, toileting, or transferring between bed and chair; additional time spent with child, including keeping him or her company, or providing direct supervision for safety reasons; arranging appointments or respite from paid or unpaid supports; attending health care appointments; transporting the child; and spending time in the hospital.

Life-Threatening Illness

Throughout my thesis I have used the term *life-threatening illness (LTI)*. A life-threatening illness has been defined as an illness or disease for which there is no reasonable hope for cure and from which children die prematurely. This definition may include a wide range of conditions, meeting one of the four following criteria (Association for Children with Life-Threatening or Terminal Conditions and Their Families & Royal College of Paediatrics and Child Health [ACT/RCPCH], 2003):

1. A condition that can be cured through available treatment, but poses a threat to one's life because treatment may not be successful in every case (e.g., cancer).
2. Conditions for which treatments will extend life expectancy, but for which there is no known cure, and are ultimately terminal (e.g., cystic fibrosis, HIV/AIDS).
3. Progressive conditions for which there is no cure, symptoms are merely managed, and palliative care may extend over many years (e.g., muscular dystrophy and Batten disease).
4. Severe neurological conditions that are not progressive, but lead to complications resulting in premature death (e.g., severe cerebral palsy).

This set of criteria was one of the factors used to determine participants' eligibility for the Caregiving Parent Study (Cadell et al., personal communication), from which the sample for the current study was extracted.

The phrase life-limiting illness is also commonly used in the pediatric palliative care literature and was applied when referencing researchers who had elected to use this term. While some researchers and practitioners view these terms as distinct, there is little consensus regarding the use of terminology. The lack of agreement on a preferred term seems to be reflective of the evolving efforts across health care settings and on ethics review committees as both strive to assure the respectful use of language.

It is important to note that the above categories are fluid in nature. As with terminology used to describe LTIs, there is a lack of consensus among pediatric practitioners when it comes to which illnesses fall under which categories. The categorization of conditions is not straightforward. Decisions are dependent on both global and individual factors. For example, though medical advances have led to improvements in treatment and symptom management in certain progressive illnesses, at the individual level a child may not have access to available treatments, or a given treatment may not be appropriate or effective given the trajectory of a child's illness or his or her prognosis.

Pediatric Palliative Care

Palliative care seeks to enhance the quality of one's life in the face of a condition that is terminal. As well as controlling pain and symptoms of a LTI, *pediatric palliative care* addresses the psychological, social, spiritual, and emotional needs of children and their families (American Academy of Pediatrics [AAP], 2000). Details regarding important differences between adult and pediatric palliative care, and special pediatric considerations, are discussed in the literature review to follow.

A Couple

The focus of this study is on the experience of couples. A *couple* is defined as two people who are cohabitating and have identified themselves as married or living as married. Throughout this thesis the term couple may be used interchangeably with such wording as parents, mothers and fathers, or partners. The couples in this study are together caring for a child with a LTI; however, the child may not necessarily be the biological child of one or both parents.

Personal Growth

Personal growth refers to the idea that individuals can experience positive life changes as they attempt to cope with a traumatic event or life crisis (Helgeson et al., 2006; Hogan & Schmidt, 2002; Joseph & Linley, 2008; Tedeschi & Calhoun, 1996; Tedeschi & Kilmer, 2005). Other terms commonly used to describe this concept are posttraumatic growth, stress related growth, adversarial growth, benefit-finding, and perceived growth. Though a number of models attempt to describe and explain the process of personal growth at an individual level, most of these models theorize that the occurrence of a highly stressful or traumatic event results in a violation of one's personal beliefs about the world and oneself. Consequently, a person will engage in various forms of meaning making or cognitive processing in an attempt to reconstruct his or her goals and beliefs, resulting in perceptions of growth through this process (Park & Helgeson, 2006).

Three general areas in which growth has been shown to occur following a crisis were identified by Tedeschi and Calhoun (1996) during the development of their posttraumatic growth model. First, self change may result in an individual feeling stronger, more self-assured, and assertive. Such positive changes may alter one's sense of competency and resilience in difficult situations. Second, changes in interpersonal relationships may result from closer relationships and a heightened appreciation for family and friends. Recognition of one's own vulnerability following a crisis may also lead to greater sharing of emotions and a willingness to ask for and accept help from peers, family, and support agencies. The third area where change may be identified is in an individual's overall philosophy and appreciation for life. Such transformations in one's values may lead to alterations in priorities, spiritual beliefs, sense of control, and the basic assumptions one may hold regarding the meaning of life (Tedeschi & Calhoun).

Individuals who have experienced personal growth as an outcome of grief have been characterized by Hogan and Schmidt (2002) as having recreated a new sense of self, becoming more compassionate, more forgiving, and more tolerant with themselves and others. Having overcome feelings of hopelessness, their outlook for the future becomes more optimistic. As a result of these reconstructions of meaning, their views of themselves and their world are positively transformed. These conclusions have been based upon research with adolescents who have lost siblings and with bereft parents. Hogan and Schmidt developed the Grief to Personal Growth model in opposition to the more constrained view that resolving grief means "returning to normal".

Chapter Three: Literature Review

To gain a complete understanding of the experience of couples caring for a child with a life-threatening illness it is necessary to first consider the context within which parents are providing care. For this reason, I begin this literature review with a description of goals and unique considerations in the provision of pediatric palliative care services. This overview is followed by a presentation of research findings in the area of parental functioning when caring for a child with a LTI. This review includes challenges of being a parental caregiver, as well as research recognizing that there is a sense of satisfaction and benefit gained through this experience. The recent call for exploration into positive outcomes of caregiving (Steele & Davies, 2006; Ylven et al., 2006) fits nicely with three areas of mounting interest in the field of social work: the potential for individuals to undergo positive change following adversity, the role of spirituality and meaning making in the healing process, and strength based assessment and intervention practices.

An overview of personal growth follows the discussion of parental caregiving. This review includes findings from a recent meta-analysis and emerging questions surrounding the phenomenon. Given the current study's focus on gender patterns, the literature review concludes with a summary of research examining gender differences in the areas of personal growth and caregiving, and an examination of growth in couples experiencing a medical crisis.

Pediatric Palliative Care

Rather than being about dying, pediatric palliative care (PPC) is about helping children and their families live to their fullest, while managing illness (Himmelstein, 2006). As stated by the AAP (2000), "The goal is to add life to the child's years, not years to the child's life" (p. 353). The following section reviews the goals of PPC and how these goals, pediatric illnesses, and symptom management differ from the adult population. Developmental and ethical considerations that are unique to PPC are also presented. Finally, the responsibility that the care team has to family members is discussed along with proposed barriers to providing quality care.

Family-centred PPC is described as the art and science of enhancing quality of life, attending to suffering, and assisting with medical decision making for children with life-threatening conditions. The first steps in palliative care are to identify the decision makers, ensure that those involved have a thorough understanding of the illness and prognosis, and establish realistic goals of care (Himmelstein, 2006). The process of palliative care involves a gradual transition, whereby the patient and family shift from a stance of hope for a cure to a state in which they accept the possibility of death. At this stage hope begins to involve other matters of importance, such as peace and understanding, management of pain, enriching relationships, a meaningful death, and concern about the fate of loved ones (Kane et al., 2000). At all stages, the overarching goal of PPC is to support the physical, psychological, social, emotional, and spiritual needs of the ill child and his or her family.

The provision of quality PPC presents a number of challenges. Palliative care guidelines and interventions that are appropriate for adults are often inappropriate for this younger cohort (AAP, 2000). The CHPCA & CNPCC (2006) outline a number of unique issues for children and families that warrant consideration. Firstly, many of the LTIs that children are diagnosed with are rare, often only affecting children. A number of the conditions affecting children are genetic; as a result, more than one child in a family may be diagnosed with a disease. An additional consideration is that pain and symptom management for children can be more complex than with adults. Children experience and express pain differently. They typically require individualized treatment and the symptoms they experience are not always well understood (CHPCA & CNPCC).

The proactive management of children's complex symptoms comprises the art of good palliative care (Himmelstein, 2006). Pain management can be a key determinant of the level of distress experienced by the ill child and his or her family. The importance of effective pain management was illustrated through a needs assessment of a pediatric palliative care program in the state of California. Interviews with 68 family members of 44 deceased children and surveys

from 446 staff members and community physicians found effective pain and symptom management to be a primary concern for all parties involved (Contro, Larson, Scofield, Sourkes, & Cohen, 2004). Family members shared that they experienced anguish associated with watching children suffer and a sense of helplessness over not being able to alleviate pain. Approximately half of the attending physicians and residents surveyed reported feeling inexperienced in their management of pain of dying children.

Unfortunately, research on pain and symptom management typically focuses on the adult population, failing to investigate best practices for treating children (Himmelstein, 2006). Despite legislation in the United States in 1997 that sparked an increase in the testing of pediatric drugs, many medications used to treat pain, nausea, and other symptoms in adults have yet to be tested or labelled for younger patients. Because physicians treating children may lack the information needed to make informed choices when administering medication, some may decide not to treat certain children, rather than risk dangerous side effects and complications (Field & Behrman, 2003).

An additional difference between adult palliative care and pediatric palliative care is the timescale involved in providing services to children and their families (Emond & Eaton, 2004; Lenton, Franck, & Salt, 2004). The trajectories of pediatric LTIs are often unpredictable. Children may require years of caregiving, potentially surviving into late adolescence or early adulthood (CHPCA & CNPCC, 2006). Whereas adult palliative care is typically synonymous with end-of-life care, wherein active treatment is no longer effective and life expectancy is measured in weeks or months, PPC involves a long-term provision of integrated services. Ideally, PPC is offered shortly after diagnosis, perhaps taking place concurrently with curative interventions, and continues over the course of an illness into the end-of-life phase and bereavement (AAP, 2000; Emond & Eaton; Field & Behrman, 2003; Lenton et al.).

Over this time course, the skills, abilities, needs, and concerns of children will change as they develop physically, emotionally, spiritually, and cognitively. Throughout this process,

ethical considerations will arise that are unique to PPC. As a child gains the capacity to understand the benefits and risks involved in treatment he or she is likely to become more involved in the decision-making process (CHPCA & CNPCC, 2006; Cincotta, 2004; Field & Behrman, 2003; Himmelstein, 2006). Examples of ethical considerations that are relevant to PPC include the child or adolescent's legal right to consent to or forego treatment, as well as the amount and type of information parents and service providers share with a child (CHPCA & CNPCC).

Not only must the palliative care team consider the health status and quality of life of the ill child, they are also committed to supporting parents throughout the various stages of illness. Their responsibility extends through the phases of end-of-life and bereavement. It is important for the team members to reassure parents and the child that they will continue to be involved throughout the child's life, as well as after death (AAP, 2000). A common theme reported by parent caregivers of children with a LTI living in the United States has been the lack of sufficient support provided by their health care teams (Contro et al., 2004; Parker, 1996). Parents also noted that physicians and health care providers ignored or discounted the information they shared with them regarding their child's condition (Parker). Researchers exploring the experiences of families of deceased children found that the majority of interviewees had experienced staff being insensitive or making remarks that resulted in ongoing pain. Parents shared that such comments contributed to more complicated grief (Contro et al.). To some degree these negative interactions may be related to a lack of preparedness on the part of PPC team members. The education and training of physicians and allied health professionals has been described as deficient when it comes to issues concerning end-of-life care for children, with few medical schools including the care of terminally ill children in their curriculum (Kane et al., 2000).

A lack of skillful communication can also be related to the misperceptions of some physicians who believe that limiting the information they share about poor outcomes is in the best interest of families. Researchers at the Dana Ferber Cancer Institute and Children's Hospital in

Boston found that parents of children with cancer, who were in their first year of treatment, reported deriving greater hope when physicians shared detailed prognostic information (Mack et al., 2007). These researchers acknowledged that hope is an individual construct; as such, feelings of hopefulness were not tied to a cure or other medical outcomes. The positive association between disclosure of information and hope was true even when there was a low likelihood for a cure. Researchers in Western Australia compared reports of parents whose children had died from cancer to parents actively caring for children with chronic or life-threatening conditions other than cancer (Monterosso et al., 2007). They found that the non-cancer group of parents had greater concerns regarding a lack of adequate communication with physicians. The non-cancer group felt that discussions about diagnosis and treatment were fragmented and the severity of the child's illness was often de-emphasized. As one parent stated, the approach taken was "too considerate."

When reflecting upon the state of PPC, it is important to note that this is a specialized field that is in its infancy. Less than 10 years ago there was very little information outlining challenges and best practices for provision of palliative or end-of-life care for infants, children, and adolescents. Within this short timeframe a number of medical institutes and residency training programs across Canada and the United States have taken steps to evaluate their own pediatric palliative care programs and improve the knowledge base and skills of individuals providing care to children and families (Hays et al., 2006; Liben, Papadatou, & Wolfe, 2008; Meyer, Ritholz, Burns, Truog, 2006; Schiffman et al., 2008; Ward-Smith et al., 2007). This undertaking seems to have been stimulated by the American Association of Pediatricians' initiative to issue a policy statement and recommendations on palliative and end-of-life care for children in the year 2000. Later that same year, the Institute of Medicine in the United States also took action to investigate the special needs and circumstances of children and their families and suggested steps that clinicians, educators, researchers, policymakers, and others could take to improve care (Field & Behrman, 2003).

In comparison to adult palliative care, where the primary focus is typically on the patient, social workers working as part of a pediatric care team must be prepared to support the child, as well as parents, siblings, and members of the medical staff (Cincotta, 2004). While acquiring greater information on medical strategies and effective communication is advantageous for physicians and nursing staff striving to provide quality care, those working with families would also benefit from an awareness of the impact caregiving has on family members. It is important to realize that there is a wide variation in how couples may be affected by the caregiving experience. The care team should also recognize that a couple's relationship is likely to impact the ability of parents to care for their child, as well as the child's ability to cope with his or her illness and eventual death. The following section will discuss functioning in parents caring for a child with a life-threatening illness.

Parental Functioning and Childhood Life-Threatening Illness

Fundamental factors known to influence an ill child's well-being include the child's personality, social environment, and family characteristics – in particular, qualities of his or her parents (Morrod, 2004). Caregiving has been described as impacting all aspects of family life. The following section provides an overview of the psychological, emotional, spiritual, physical, and financial consequences documented in the literature on family and parental functioning in the context of childhood life-threatening illness (Cincotta, 2004, Cook, 1984; Field & Behrman, 2003; Jones & Neil-Urban, 2003; Kane et al., 2000; Monterosso et al., 2007; Parker, 1996; Steele & Davies, 2006). The effects that caregiving has on family dynamics, including parenting and the marital relationship, is also reviewed (Cook; Davies et al., 2004; Jones & Neil-Urban; Morrod; Parker). The section concludes with a presentation of some of the strategies that parents have found beneficial to their ability to cope.

While the literature has shown that the majority of parents prefer to care for their child at home and do not typically perceive this act as a burden, caregiving can be extremely stressful for many parents (Emond & Eaton, 2004; Himmelstein, 2006). Although parents may cherish every

minute of care they provide to their ill child, the excessive strain from a physically, emotionally, and technically demanding regimen of caregiving poses an ongoing risk to a parent's mental and physical health (Field & Behrman, 2003). The psychological and emotional well-being of parents caring for a child with a LTI is affected by fear, guilt, chronic grief, and a sense of perpetual helplessness. In a study of parents of children with cancer and blood disorders, 87% of the participants reported that feeling helpless was a key issue, as well as fearing that they would not be able to cope if their child died (Cook, 1984). Fathers of children with cancer who took part in a focus group shared that they experienced a strong sense of helplessness over not being able to protect their children or wives from pain (Jones & Neil-Urban, 2003). As parents grieve the loss of a healthy child, they may also be fraught with guilt over what they did to cause their child's illness (Parker, 1996).

Furthermore, the uncertainty that parents live with throughout the trajectory of their child's illness has been reported by parents as causing additional stress and anxiety. Parents are faced with the ambiguity of diseases that are rare and unpredictable (Parker, 1996), as well as the uncertainty associated with treatment and interventions (Cohen, 1995; Jones & Neil-Urban, 2003). Even when medical conditions are common, children's general physiologic resiliency complicates predictions about survival and other outcomes (Field & Behrman, 2003). Qualitative inquiry into the experience of parents of children with cancer found that uncertainty was a constant. Even when the disease was considered to be in control or in remission parents described uncertainty as "intruding" in their lives (Cohen). Triggers of uncertainty found to increase anxiety for these parents included medical appointments, body changes, certain words or questions, changes in treatment, the potential of negative outcomes, new developmental demands, and nightmares. The unknowns surrounding a child's quality of life, development, and life-expectancy are endless.

Uncertainty may also influence parenting practices and parent-child dynamics, serving as an additional risk factor for psychological distress. Parent caregivers may question their

philosophy on discipline or be unsure whether the expectations they have of their child are appropriate (Berge & Holme, 2007). Parents may be uncertain about the best way to communicate with their child, what information they should share, or how to broach issues related to illness and what the future may hold. Communication can be further complicated when a child intentionally remains silent in an attempt to protect parents, possibly leading to feelings of isolation for both the parent and child (AAP, 2000).

As parents struggle to deal with their issues of loss, they must also be aware that ill children are grieving their own set of personal losses, for example the loss of skills and abilities, independence, contact with friends, and the ability to participate in school and faith communities (Himmelstein, 2006). While parents have reported struggling with issues related to coping with changes in their children's ability or activity levels, knowing how to help their children cope with disease-related changes and helping them to maintain a 'normal' lifestyle are also challenges (Monterosso et al., 2007).

Parents must also remain conscious of the emotional well-being of healthy children in the family. Siblings may feel abandoned, left out, or responsible in some way for the plight of their ill brother or sister (Cincotta, 2004; Himmelstein, 2006). Researchers examining predictors of psychological adjustment found that siblings of children with disabilities had better adjustment outcomes when they were from a family with effective communication and problem solving skills (Giallo & Gavidia-Payne, 2006), thus illustrating the essential role of parents in facilitating their children's well-being.

In times of suffering people often turn to religion in search of purpose, comfort, or direction. When a child is diagnosed with a LTI there is the potential that one's faith and spiritual beliefs will be challenged. This situation typically leads parents to struggle with existential questions as they search for meaning and acceptance (Kane et al., 2000; Steele & Davies, 2006). Researchers exploring the experience of parents caring for a child with a neurodegenerative LTI found that many parents reported that pondering spiritual questions was an essential component

in the process of finding meaning and achieving acceptance (Steele & Davies). Though the experience of parenting a child with a LTI was found to reaffirm or strengthen the faith of some, it caused others to feel discouraged or let down by their faith and church. This experience resulted in feelings of anger and a sense that they were being unfairly punished by God. These feelings had the potential of ultimately causing parents to give up on God. Parents who lost their faith could find little meaning in their experience. Alternatively, parents who drew upon their faith were more satisfied with their lives and were more likely to find acceptance (Steele & Davies).

Faith was one theme that emerged in an investigation of the priorities and recommendations of parents for end-of-life care and communication. This qualitative study involved interviews with 56 parents of children who had died following the withdrawal of life support in one of three pediatric intensive care units in Boston (Meyer et al., 2006). Children ranged in age from newborn to 18 years of age and died from a full range of medical and surgical diagnoses. Faith played a central role in the efforts of many to make meaning of the situation. Praying for God's help offered comfort, as did seeking counsel from religious personnel and receiving support from faith communities. Others parents acknowledged a deep spiritual distress. As one parent told the interviewer, "Just when I needed my faith, I hated it, for deceiving both my child and myself" (Meyer et al., p. 653).

The physical demands that come with providing care to a child with a LTI typically present a range of challenges for parents, unlike spiritual consequences that may lead to either positive or negative outcomes. The physical strain associated with caregiving has been shown to result in various injuries, migraine headaches, hives, anemia, and exhaustion. The physical strain of lifting, transferring, and bathing children has been reported by parents to increase over time as children grow and their mobility deteriorates (Steele & Davies, 2006). The physical demands of caregiving have been shown to influence the well-being of family members. For instance, researchers have shown that the severity of a child's condition and his or her level of independent functioning is an important predictor of maternal depressive symptoms (Berge, Patterson, &

Rueter, 2006). Caregiving parents have reported experiencing months, or even years, of sleepless nights. The considerable amount of energy expended securing services and resources for their children only adds to the exhaustion (Steele & Davies).

Monterosso et al. (2007) employed interviews to collect both quantitative and qualitative data from two groups of Western Australian parents: those who were actively caring for a child with a life-threatening or chronic illness that was not cancer, and bereaved parents who had cared for a child with cancer. Through this process the researchers documented a number of differences in the experiences of the two groups of parents. Parents of children with a non-cancer related LTI reported that the complexity and long-term duration of care contributed to a number of problems, including physical exhaustion, inability to take holidays, and general health problems, such as musculoskeletal problems. Thirty-nine percent of the non-cancer group rated their health as fair or poor. The non-cancer group received significantly less support from extended family and relied more on in-home and residential respite support (Monterosso et al.).

Many of the routine tasks parents of healthy children take for granted can be especially burdensome when caring for a child with a serious illness. Canadian researchers interested in the process of parenting a young child with a life-threatening heart disease conducted multiple interviews with mothers and fathers of nine children ranging in age from 2 months to five years (Remple & Harrison, 2007). All children had undergone surgery for their heart condition. Parents of infants had to demonstrate their ability to tube-feed their babies before being discharged from the hospital. All parents were faced with the daily responsibilities of monitoring their children, as well as providing oxygen therapy, wound care, and medication management. Given the need to protect their sons and daughters from infections, parents had to be especially vigilant that the home environment was as healthy as possible (Remple & Harrison).

As well as the psychological, emotional, spiritual, and physical consequences of caring for a child with a LTI, many parents have reported experiencing financial difficulties (Corden et al., 2002; Morrod, 2004; Parker, 1996). Financial challenges stem from medical and equipment

expenses not covered by insurance, the cost of attending appointments, paying for child and respite care, and time away from work. These families are often young and lack the resources that are usually accumulated over time (CHPCA & CNPCC, 2006). Twelve couples and four single mothers who took part in interviews two years after the death of their child all reported being negatively impacted financially by the death (Corden et al.). The financial stress experienced by the bereaved parents was typically a reflection of circumstances during the child's life. Parents reported that a reduction in work hours or having to give up employment, having to pay for a dependable vehicle, expenses for travel, telephone bills, and the cost of equipment incurred throughout the course of a child's illness contributed to their financial burden. These reports are consistent with research exploring the experiences of parents actively caring for a child with a LTI. Monterosso et al. (2007) found that 59% of parents caring for a child with a condition other than cancer experienced a high degree of financial strain. These parents were able to work fewer hours than parents who had cared for a child who died from cancer and care extends over many years.

In addition to the individual distress associated with caring for a child with a LTI, the functional dynamics within the family are also affected (Kane et al., 2000; Ylven et al., 2006). In a literature review on families where a child had a chronic illness, family variables such as adaptability, conflict, and cohesion were found to contribute to the overall adjustment of the ill family member (Knafl & Gillis, 2002). A number of factors, including cultural context and the type and severity of the child's disease, have been shown to influence family functioning (Knafl & Gillis). Researchers of a study of particular relevance to families coping with a LTI found that families had lower perceptions of cohesion when a child had Batten disease, compared to families where the child had a less serious neurological condition (Labbe, 1996, as cited in Knafl & Gillis). In a separate study, parents with a strong sense of cohesion were shown to view their child's disability as a challenge, whereas those with weak cohesion were more likely to see it as a threat (Olsson & Hwang, 2002, as cited in Ylven et al.). Overall, it appears that a family's sense

of cohesion in the context of childhood disability and illness is an attribute that strongly influences positive family functioning in everyday life (Ylven et al.)

Even in cases where family cohesion has been shown to improve with time, parental closeness may continue to suffer under the stress of caregiving (Knafl & Gillis, 2002). Researchers have repeatedly documented the strain that may be placed on the marital relationship (Jones & Neil-Urban, 2003; Monterosso et al., 2007; Morrod, 2004). Though some couples cope remarkably well, seeing one another as a strong support and an important resource for sharing problems (Yeh, Lee, Chen, & Li, 2000), other couples struggle to maintain the integrity of their relationship (Cook, 1984; Davies et al., 2004; Parker, 1996). Fathers of children with cancer shared that their relationships with their wives were placed “on hold,” because caring for their child, not romance, was their priority (Jones & Neil-Urban, 2003). Similarly, mothers of children with cancer and other blood disorders reported that their maternal obligations came first, spousal duties second (Cook). Although health care providers may recognize that a couple is having relationship difficulties they may not feel confident in initiating dialogue; this raises the question of who is responsible for supporting couples in a pediatric health care setting? (Morrod).

Stress within the relationship may be further exacerbated by the duties and responsibilities each parent feels they are expected to undertake. Caring for a child with a LTI has the potential to accentuate traditional gender roles. This division of labour may potentially leave one or both parents feeling resentful or isolated from the family, contributing to depressive symptoms and marital dissatisfaction (Berge et al., 2006; Brown & Barbarin, 1996; Morrod, 2004). Gender differences in caregiving are discussed in greater detail in a separate section to follow.

Although historically the majority of research has focused on the negatives associated with caregiving, some researchers have identified strategies that parents have found beneficial to their coping. Parents have reported that gathering information and increasing their knowledge regarding their child’s disease and treatment increased their sense of competence (Remple &

Harrison, 2007; Steele, 2002; Yeh et al., 2000). Finding ways to release negative emotions, staying optimistic, and searching for spiritual meaning have also been shown to be helpful (Yeh et al.). Furthermore, parents have reported that taking on the role of advocate for their child has contributed to their satisfaction as a caregiver (Jones & Neil-Urban, 2003; Steele).

Paralleling the growing interest in strategies to facilitate coping is a call for further inquiry into potential sources of satisfaction and benefits for parental caregivers (Steele & Davies, 2006; Ylven et al., 2006). Exploring the positive impact of caregiving on parents will provide a more complete understanding of this experience. An area suggested for further exploration involves examining personal growth associated with caring for a child with a LTI (Steele & Davies). The following section will provide an overview of the concept of personal growth and recent research in this area.

Personal Growth

Over the past decade, research focusing on stressful life events and crises has expanded to include positive outcomes (Helgeson et al., 2006; Joseph & Linley, 2008; Park & Helgeson, 2006). Although the discourse on trauma-reaction has been predominantly based upon medical model and illness ideology, an emerging interest in strength, resilience, and growth represents a significant shift away from the traditionally deficit-oriented approach (Joseph & Linley; Tedeschi & Kilmer, 2005). This interest, in what has been coined positive psychology, has grown out of recognition that researchers and clinicians have been overly focussed on negative aspects of the human experience. In order to gain a balanced, more complete, and holistic perspective of what it means to be human, equal attention must be paid to the positive sides of such experiences. It is not possible to understand growth without considering the distress that precedes it; likewise, we cannot fully understand recovery from posttraumatic stress without acknowledging the possibility of growth (Joseph & Linley). Consistent with this paradigm shift, there has been a recent escalation in research exploring the phenomenon of personal growth. Well over half of the 77 articles examined in a recent meta-analysis on benefit finding were published in the five year

period preceding the review (Helgeson et al.). What follows is a synopsis of research findings examining positive change in the context of traumatic or stressful life events, proposed processes contributing to this transformation, and potential moderators of growth.

The belief that loss, grief, and various forms of life struggles can lead to positive transformations, such as personal growth, is an idea that has been accepted since ancient times (Calhoun & Tedeschi, 2006; Hogan & Schmidt, 2002; Joseph & Linley, 2008). However, what is relatively new is the systematic manner in which researchers in the fields of psychology, counselling, psychiatry, and social work have come to investigate positive outcomes following a life crisis (Calhoun & Tedeschi). Included in this growing body of literature are studies documenting the occurrence of growth in the context of illness, disability, and bereavement. Recent studies have explored growth in bereaved parents of children (Hogan & Schmidt; Polatinsky & Esprey, 2000; Riley, LaMontagne, Hepworth, & Murphy, 2007), caregivers who had friend or family member die from complications related to HIV/AIDS (Cadell, 2007; Cadell, Regehr, & Hemsworth, 2003), parents of children with Down Syndrome (King & Patterson, 2000), those who have recovered from SARS (Cheng, Wong, & Tsang, 2006), adolescent cancer survivors and their parents (Barakat, Alderfer, & Kazak, 2006), and adult cancer survivors and their partners (Manne et al., 2004; Thornton & Perez, 2006; Weiss, 2004). Although there has been a call for research examining personal growth in families actively caring for a child with a LTI (Steele & Davies, 2006), this group is not yet represented in the literature.

As the literature has acknowledged, highlighting growth is not intended to detract from the distress and discomfort that comes with a crisis or trauma. Rather, the process of growth is presented as occurring concurrently with the negative aspects of such events (Calhoun & Tedeschi, 2006; Joseph & Linley, 2008; Park & Helgeson, 2006). The realization that positive emotions and psychological states persist amidst chronic and severe stress related to caregiving and bereavement led Folkman (1997) to propose a modification to traditional theories of coping that focused on the regulation of distress. This insight was inspired by a longitudinal study

exploring the experience of men whose partners were dying from AIDS. In Folkman's study, men from the San Francisco Bay area, who had self-identified as gay or bisexual, took part in face-to-face bi-weekly interviews about their experience of actively caring for their dying partner. The men also completed a series of questionnaires related to their psychological state, coping, and religious/spiritual beliefs. Folkman concluded "unequivocally" that both negative and positive psychological states were common throughout caregiving and bereavement.

A literature review exploring growth and psychological distress found a range of associations between the two constructs, leaving the reviewers to suggest that they should not be viewed as two ends of a continuum, but rather as two separate and independent dimensions. As such, high scores on one dimension do not necessarily imply low scores on the other (Linley & Joseph, 2004). For example, interviews with caregivers of someone who had died from complications related to AIDS showed that even among participants who reported the most growth distress remained high (Cadell, 2007). Within the same population, the reverse was also true (Cadell & Sullivan, 2006). That is, individuals who reported little or no growth on the PTGI shared positive outcomes associated with personal growth when they took part in qualitative face-to-face interviews. Statistical analysis carried out as part of a meta-review suggested that benefit finding and measures of distress are frequently unrelated (Helgeson et al., 2006). The notion that growth and distress can co-occur in various permutations was illustrated in a mixed methods study conducted with 150 families of children who had completed treatment for cancer at The Children's Hospital of Philadelphia (Barakat et al., 2006). Whereas reported posttraumatic growth and symptoms of posttraumatic stress were positively correlated for the adolescent cancer survivors, there was no relationship found between growth and stress scores of mothers or fathers.

While the idea that personal growth and psychological distress can co-occur following trauma or a severe crisis may at first seem counterintuitive, recognizing this relationship has important clinical applications. In an 18-month longitudinal study investigating perceptions of the benefits and costs related to the SARS outbreak in China in 2003, it was discovered that those

who adjusted the best had identified both aspects of the experience (Cheng et al., 2006).

Participants in this study included 70 SARS recoverers and 59 family members of a separate group of individuals who had recovered from the illness. Those who reported only finding benefits were characterized as highly defensive and experienced a loss of psychosocial supports over time. In contrast, participants who shared a mixed account of benefits and costs had lower levels of defensiveness and future accruals in psychosocial resources over time.

Empirical evidence documenting the relationship between growth and mental and physical health has been inconsistent. While some researchers have identified positive outcomes associated with perceived growth, others have shown the inverse, or no relationship at all (Park & Helgeson, 2006). Only recently, with the noted increase in research focussing on growth, has there been enough studies to conduct a statistical review of findings (Helgeson et al., 2006). In a recent meta-analysis, Helgeson et al. examined the relations of benefit finding to psychological and physical health. It was concluded that benefit finding was related to certain aspects of better mental health outcomes. Specifically, the literature indicated outcomes of less depression and greater positive well-being.

Paradoxically, it has also been determined that benefit finding is related to more intrusive and avoidant thoughts about the stressful event (Helgeson et al., 2006; Linley & Joseph, 2004). A number of researchers have suggested that intrusive thoughts about a crisis are an indication that individuals are engaging in cognitive processing and meaning making. As such, these seemingly maladaptive thoughts may be essential to the process of growth (Helgeson et al.; Park & Helgeson, 2006). Support for this idea comes from studies where participants have completed writing exercises or journaling. Such writing studies have demonstrated increased levels of forgiveness (McCullough, Root, & Cohen, as cited in King & Patterson, 2000), trauma resolution (King & Miner, 2000, as cited in King & Patterson), and perceived growth (King & Patterson). Researchers of one study discovered that parents who had written more elaborate accounts of goals they had imagined for themselves and their child before learning their child had Down

Syndrome had heightened levels of stress-related growth when follow-up was conducted two years later (King & Patterson). The sample of 67 mothers and 24 fathers was recruited for this study through support networks in Dallas. The researchers concluded that there was a positive correlation between the degree to which an individual was able to explore and contemplate lost goals and reports of perceived growth.

In the presentation of their grief to personal growth model, Hogan and Schmidt (2002) referenced four early models of personal growth, including: Janoff-Bulman's (1992) theory of how individuals reconstruct assumptions about themselves and the world following a traumatic event, Nerken's (1993) "Grief to Reflective Self" theory, Calhoun and Tedeschi's (1998) posttraumatic growth model, and a version of the grief to growth model based on the bereavement process of adolescents who had experienced the death of a sibling (Hogan, 1987; Hogan & DeSantis, 1996, all four models as cited in Hogan & Schmidt, 2002). As they point out, in all four of these models personal growth is preceded by intrusive thoughts, memories, and images, as well as a preoccupation with the traumatic event.

It has been speculated that a period of contemplation and reflection may be necessary for an actual transformation to occur, with growth only emerging following a period of inquiry and consideration (Helgeson et al., 2006; Linley & Joseph, 2004; Park & Helgeson, 2006). Through meta-analysis it was determined that benefit finding was more strongly related to positive affect and less depression when more than two years had passed since the traumatic event. In contrast, benefit finding was related to less anxiety when time since the event was less than two years. It would appear that measures of benefit finding taken soon after a stressful experience may reflect a cognitive strategy used to reduce distress, rather than being indicative of actual growth (Helgeson et al.).

The question of whether people manufacture positive changes in an attempt to reduce the distress that accompanies a traumatic event has been addressed by some researchers. Some have reported that perceptions of growth are indeed illusionary (Frazier & Kaler, 2006, as cited in Park

& Helgeson, 2006). Others have proposed that such misperceptions are a reflection of distortions in one's recollection of one's past self, where persons view their previous selves and world as worse than they actually were (McFarland & Alvaro, 2000, as cited in Park & Helgeson). However, it has been suggested that even reports of growth that are assumed to be illusory may serve as a pathway to actual growth (Park & Helgeson). Because many reports of growth cannot be connected to any measureable indicators of personality, resource, or behavioral changes, it has been suggested that subjective reports of perceived growth may be more closely tied to psychological outcome than observable markers. Here an analogy can be made to reports of social support, whereby perceived support has been found to be more important than actual support received (Park & Helgeson).

What demographic variables may serve as moderators of growth is an additional question under investigation. Researchers employing structural equation modelling to explore factors contributing to growth identified spirituality, social support, and stressors to all be positively related to the construct (Cadell et al., 2003). A younger age and being of a minority race or ethnicity have been found to be associated with more benefit finding, whereas socioeconomic and marital status appear to be unrelated to benefit finding (Helgeson et al., 2006). A review of the literature also revealed that the personality variables of self-efficacy, hardiness, and high self-esteem were related to greater reports of growth (Linley & Joseph, 2004), as well as greater optimism and religiosity (Helgeson et al.).

Of particular relevance to the current study is confirmation through statistical meta-analysis that women engage in more benefit finding than men. However, this finding has been inconsistent across studies and may be affected by the nature of the trauma being investigated. It also remains unclear whether gender influences psychological and physical outcomes associated with benefit finding (Helgeson et al., 2006). An awareness of the demographic variables that may promote or impede personal growth and the outcomes associated with this change is important for professionals supporting individuals and families. This understanding not only informs

professionals of groups that may be less likely to engage in the process of benefit finding, but can also provide insight into personal factors and characteristics that may promote positive changes that accompany growth. Further consideration of potential gender differences associated with personal growth and caregiving will be discussed in the following section.

Gender Differences in Personal Growth and Caregiving

The limited information available on how gender may have an effect on perceptions of growth is contradictory. The following section outlines some of the conclusions that have been made in this area and presents reasons why more investigation into differences and similarities between men and women has not taken place. Findings from a recent study on the experiences of fathers who have a child with a life-limiting illness will be used to introduce the topic of gender issues in caregiving. Paternal perceptions of social-cultural influences, social support, and internal conflicts related to adopted roles within the family will also be discussed.

As mentioned above, it appears that women engage in more benefit finding than men. However, this finding has been inconsistent in the literature and has been shown to be confounded by the type of trauma being studied (Helgeson et al., 2006). In the initial testing of the Posttraumatic Growth Inventory (PTGI), using a large group of undergraduate students who had self-identified as experiencing a significant negative event in the past five years, Tedeschi and Calhoun (1996) found that women experienced significantly more growth. The greatest differences were noted in the areas of spirituality and relationships with others. Smaller differences were found in perceptions of new possibilities and personal strengths, though women experienced more positive change in these areas as well.

While early findings that men and women experience growth differently have found some support, other reports have disputed this conclusion arguing that significant gender-related differences do not exist. Researchers of a study with individuals who were indirectly exposed to the 2004 Madrid train bombings claimed that women scored higher on measures of posttraumatic growth (Val & Linley, 2006); however, examination of the results shows that these differences

were not statistically significant. Similar findings have been documented in the literature on personal growth in the context of bereavement and illness. Researchers exploring the perceptions of benefit in bereaved parents found that, although the overall PTGI score and four of the five index scores (Relating to Others, New Possibilities, Personal Strength, and Spiritual Change,) were higher in the group of mothers, differences were not significant (Polatinsky & Esprey, 2000). In a more recent study, no significant differences existed between mothers and fathers who had a child die (Engelkemeyer & Marwit, 2008). The 111 parents who participated in this quantitative study had a child under the age of 25 years die from an accident, illness, or homicide. A review of the research examining posttraumatic growth in the context of cancer strongly supports the notion that men and women do not differ in their experiences of growth (Stanton, Bower, & Low, 2006). This conclusion was consistent across all eight diverse study samples, which encompassed a range of diagnoses, ages, nationalities, stages of disease, and methods used to collect data.

There is a paucity of literature on gender-related differences in personal growth for a number of reasons. Due to the nature of the traumas investigated, researchers may sample either women or men, for instance survivors of breast cancer or prostate cancer. Thus, the type of trauma studied may serve as a confounding variable when attempting to draw conclusions about growth research (Helgeson et al., 2006). Sample sizes are also often too small to draw meaningful conclusions (Tenner & Affleck, 1998).

After reviewing the early literature on gender-related differences in posttraumatic growth, Tenner and Affleck (1998) stated that although they suspect that differences do exist, these differences may be elusive. A decade later, the inconsistencies and contradictions in the literature on the association between gender and personal growth are evidence that drawing reliable conclusions remains a challenge. When Tedeschi and Calhoun (1996) first documented gender-related differences using the PTGI, they suggested that traumatic events have a greater effect on women because women are better able to learn or benefit from difficult life experiences.

Although there is no research examining perceived growth in parents caring for a child with a LTI, recent exploration into the experiences of these mothers and fathers would suggest a much more complex set of influences than Tedeschi and Calhoun originally proposed.

Evidence of the strong influence of sociocultural factors on caregiving parents comes from a recent qualitative study examining the experience of fathers who have a child with a life-limiting illness (Ware & Raval, 2007). One of the main themes that emerged during the interviews was the manner in which men perceive themselves as different from women. Although no question pertaining to gender differences was included in the semi-structured interview, all eight of the fathers firmly identified differences in the way they coped and adjusted to their child's illness, compared to their female partners. The fathers spoke of the social-cultural stereotypes and attitudes that have limited their ability to respond emotionally, seek support, and communicate with others about their situation. They also spoke of growing up in an environment that precluded boys and men from openly expressing their emotions. Whereas women are encouraged to share their feeling and inner thoughts, a common belief of the men was that they are expected to present in public as being strong and coping, although privately they may be in considerable turmoil (Ware & Raval). The finding that fathers receive less support than mothers was documented in a longitudinal study of parents of children with cancer (Wijnberg-Williams, Kamps, & Hoekstra-Weebers, 2006). Inadequate support for fathers was shown to have negative effects over the five-year study period, with lack of support being positively correlated with levels of distress. Corresponding to this finding is research showing that general social support and marital support were associated with greater posttraumatic growth in spouses of women with breast cancer (Weiss, 2004).

In addition, the fathers in Ware and Raval's (2007) study identified various ways they perceived being treated differently by health care services and the education systems. The men felt major gains could be made if service providers shifted their focus from women to both parents. A group of fathers of children with cancer had a similar sense regarding the health care

system. The men reported that the structural constraints of hospitals limited their ability to help their sick child. The fathers spoke of feeling excluded from some of the health care work, due to their typical working hours and the scheduling of medical conferences and their child's treatments (Clarke, 2005). Based on findings from a much older study exploring gender issues in caregiving (Cook, 1984), fathers feeling conflicted over their role within the family is not a modern-day occurrence. The fathers in Cook's study, who had children with cancer or a blood disorder, described being pulled in opposite directions by their work and family obligations. Though they wished they could spend more time with their children and wives, doing so was a challenge. The need to work resulted in fathers often feeling left out of their child's care, isolated, and ill-equipped to access support.

As researchers of these studies have illustrated, caring for a child with a LTI has the potential to accentuate traditional gender roles (Brown & Barbarin, 1996; Morrod, 2004). Research has found that mothers spend most of their time dealing with the medical aspects of their child's illness and tending to household chores, while fathers spend most of their energy thinking about and dealing with medical and household finances (Brown & Barbarin). In the context of a couple's relationship, fathers are typically expected to take on the role of supporter to the rest of the family with their needs often going unacknowledged. Although a wife may evaluate her husband as being reassuring and ready to move on, the reality may be that fathers are highly distressed and fearful of becoming overwhelmed and incapacitated by their own grief (Morrod, 2004). Fathers caring for a child with a LTI reported that their roles related to work and childcare limited their opportunities to meet their emotional needs. Furthermore, the fathers viewed the roles of their partners as more emancipating and emotionally enabling (Ware & Raval, 2007).

Until recently, the majority of research on childhood illness has focused on negative mental health outcomes of mothers, neglecting to consider the voice of fathers. This underrepresentation of fathers in research has been one way in which male caregivers of children have

been marginalized by health care professionals and researchers (Macdonald et al., in press; Morrod, 2004). The authors of a literature review exploring positive functioning in families of children with disabilities or chronic illnesses had to exclude over half of the articles considered (51 out of 81) because, despite claiming to report “family functioning”, the samples consisted 100% of mothers (Ylven et al., 2006). Reviewers of North American pediatric palliative care research published from 1988 – 2008 and claiming to report on “parental” perspectives found that in the 45 articles that met criteria 75% of all participants were mothers (Macdonald, et al.). When articles that had couples in the sample were extracted from the analysis the ratio of mother participants increased to 84%.

An understanding of how gender may influence caregiving and personal growth will provide direction for counsellors and health care professionals in their pursuit of effective intervention strategies for couples caring for a child with a LTI. Findings may also assist couples in better understanding the experience of their partner. The following section discusses the literature on growth in couples.

Personal Growth in Couples Experiencing a Medical Crisis

Only a handful of studies have examined personal growth in couples. These studies have illustrated the influence of interpersonal relationships and couple dynamics on perceptions of personal growth and distress (Manne et al., 2004; Ruvolo & Brennan, 1997; Thorton & Perez, 2006; Weiss, 2004). The following section summarizes research that has examined growth at the couple-level and relationship variables found to be associated with growth. Special attention is given to the roles of perceived support, positive reframing, and communication.

In a literature review examining the role of social and family support following a life crisis it was found that, overall, a stable and cohesive family seems to provide a protective and stress-resistant function; thus enabling individuals to confront and benefit from life crises (Schaefer & Moos, 1998). With respect to couples in particular, a high level of marital intimacy was associated with a less depressive mood in cardiac patients, and women with rheumatoid

arthritis who had supportive husbands were found to adjust better psychologically, engage in cognitive restructuring, and seek out more information (Schaefer & Moos). Researchers of a recent study on psychological adjustment in women with rheumatoid arthritis showed that high couple congruence regarding beliefs about the controllability of the condition and the unpredictable and cyclic nature of the illness resulted in wives faring better (Sterba et al., 2008). The women also showed better psychological adjustment when the beliefs shared by couples were more optimistic (Sterba et al.). Although these studies did not examine growth, there are a number of parallels between the study findings reported and variables known to enhance individual growth, such as the positive correlation between optimism and benefit-finding (Helgeson et al., 2006; Linley & Joseph, 2004), and the roles of social support (Cadell et al., 2003; Weiss, 2004) and support satisfaction in facilitating growth (Linley & Joseph). Furthermore, these studies clearly illustrate the strong influence that couples have on one another's well-being and psychological adjustment.

A statistical meta-analysis of benefit finding and marital status indicated that the two are not related (Helgeson et al., 2006). However, investigators of a study on perceptions of benefit following the death of a child found that individuals who were married had significantly higher reports of growth related to an appreciation of life, compared to single-parents (Polatinsky & Esprey, 2000). Married parents also had a higher mean PTGI Total Score, along with higher scores on the indices of Relating to Others, New Possibilities, and Personal Strength, however, these differences were not significant. In general, unmarried caregivers of children with cancer have reported experiencing greater degrees of guilt, anxiety, somatization, and internalized burden, compared to their married counterparts (Bonner, Hardy, Willare, & Hutchinson, 2007).

The association between marriage and personal growth is more likely related to the nature of a couple's relationship, rather than marital status alone. Researchers exploring posttraumatic growth in husbands of 72 women diagnosed with early stage breast cancer between 1 and 5 ½ years previous found reports of growth to be strongly related to qualities of the marital

relationship and general social support (Weiss, 2004). In fact, all five factors measured by the Posttraumatic Growth Inventory were positively and significantly correlated with marital support and depth of commitment. Researchers of a study with 82 prostate cancer survivors treated at a cancer centre in California showed that emotional support contributed to increased levels of growth one year after surgery (Thornton & Perez, 2006). Overall, spousal support and marital satisfaction appear to have a strong influence on reducing role strain and enhancing general well-being (Berge et al., 2006; Purdom, Lucas, & Miller, 2006), and more specifically, on perceptions of personal growth.

Positive reframing is a second factor found to predict growth in the context of a couple's relationship. Coping using positive reframing has been strongly associated with posttraumatic growth in survivors of prostate cancer and their partners (Thornton & Perez, 2006). A relationship between positive reappraisal and growth congruency in breast cancer survivors and their husbands has also been documented (Manne et al., 2004). Over an 18-month-period growth scores of survivors and their partners became more similar to one another when the partner was above average in the use of positive reappraisal. When the discrepancy between scores of a couple increased, the growth of the wife tended to become greater than that of her partner. In light of findings showing a positive correlation between greater growth in breast cancer survivors and posttraumatic growth scores of husbands, it has been suggested that exposure to a wife who makes positive interpretations of her cancer experience has a contagious effect, thus resulting in a transmission of growth between marital partners (Weiss, 2004).

Communication is a third factor shown to influence growth when examined at the couple-level. Mutual constructive communication, defined as the mutual discussion of issues, expression of feelings, understanding of one another's views, and the resolving of issues, has been shown to be related to less distress and greater relationship satisfaction for breast cancer survivors and their partners (Manne et al., 2006). Emotional expression, being able to share inner feelings with one's significant other, was an important predictor of growth in breast cancer survivors (Manne et al.,

2004). Whereas emotional expression was predictive of survivors' growth, it was the processing of emotions that predicted growth in partners, the vast majority of whom were men. Of particular relevance to these findings, which document the importance of communication style in couples and opportunities for women to share emotions, is the work of researchers showing that fathers of children with a LTI often feel that social-cultural stereotypes and attitudes serve to limit their ability to respond emotionally and communicate with others about their situation (Ware & Raval, 2007). These perceived restrictions may hinder the positive changes fathers might otherwise experience, as well as serve to limit opportunities for mothers to engage in experiences that could facilitate their personal growth. Consistent with this suggestion are findings showing that survivors of breast cancer whose partners were above average in their emotional expression, defined as a willingness to discuss their own feelings, reported greater posttraumatic growth compared to women whose partners were below average in emotional expressiveness (Manne et al., 2004). The researchers propose that having a more expressive partner provides opportunities for open communication and more comfort for women to discuss concerns, thus serving to enhance personal growth.

The above studies illustrate that growth is not an individual activity and attest to the importance of considering the dyadic context when exploring patient and partner growth (Manne et al., 2004; Thornton & Perez, 2006; Weiss, 2004). It has been proposed that couples can best be viewed as an interdependent system, within which members support one another's growth (Weiss). With respect to the current study, it is difficult to know whether personal growth in couples caring for a child is comparable to couples where one partner has been diagnosed with an illness and the other partner, although very much impacted by the event, takes on a caregiving and supportive role. Due to an absence of research exploring personal growth in couples who are together caring for a child with a LTI, it seems too early to make predictions about what parallels might exist between these two groups.

Summary and Limitations of Research

Research into the experience of personal growth in mother-father dyads is an essential step in the development of effective intervention strategies designed to address the needs and identify the strengths of couples caring for a child with a LTI. While there has been a great deal of research examining the consequences of caring for a child with a chronic illness or disability, few studies have focused specifically on pediatric illnesses that are terminal or life-threatening. Investigations seeking to explore the experiences of parents who have been told there is no cure for their child's condition, and consequently he or she will die prematurely, are necessary to increase the understanding that members of the pediatric palliative care team have regarding the realities of these families.

It is essential that members of the PPC team do not neglect to consider, or underestimate, the manner in which family dynamics, including the marital relationship of the parents, impact upon the ill child's adjustment and well-being. Although, the literature has documented the challenges that parenting couples face when caring for an ill child, there is an absence of studies focusing on how couples may benefit from the caregiving experience and how the process of growth may evolve within the context of the spousal relationship. Of relevance to investigations into personal growth in couples is the question of whether men and women experience this process in a similar manner, or the degree to which difference may exist between the two groups.

Conclusions in the literature exploring gender differences appear to be mixed. Clinicians must remain cognizant of the variation in patterns of growth and distress that may exist across genders, as well as the overlap that exists between genders. Seeking an answer to the question "how is personal growth experienced in couples caring for a child with a life-threatening illness?" will provide insight into the existence of differences and similarities in the manifestations of growth in mothers and fathers. These findings will have relevance for professionals and volunteers working with caregiving families and will serve to inform clinical interventions for couples requiring support.

Chapter Four: Methodology

Research Design

This research was designed to examine personal growth in couples caring for a child with a life-threatening illness. Comparing the perceptions of a mother and a father, who are caring for the same child, enhances the understanding of how gender may affect the manifestation of personal growth. Examining the relationship between selected demographic variables and personal growth provides information regarding the similarities and differences in factors serving to influence growth in mothers and fathers. By investigating congruence within couple-dyads, this study provides insight into whether spouses/partners are more or less likely to experience similar levels of personal growth and where couples' scores fall in relation to one another.

Although cross-sectional investigations into perceptions of growth have explored a range of populations, the current study casts the focus on a group yet to be investigated – couples who are together caring for a child with a LTI. In addition to adding to the personal growth literature, this introduction to the experience of caregiving couples serves as a valuable contribution to the areas of pediatric palliative care and parental functioning in the context of childhood chronic illness and disability. This study was designed to achieve three goals.

Goal One – Explore the extent of gender differences in personal growth by comparing posttraumatic growth scores of mothers and fathers.

Of the six personal growth scores generated from the Posttraumatic Growth Inventory (Total Growth, Relating to Others, New Possibilities, Personal Strength, Spiritual Change, and Appreciation of Life) I hypothesized that no significant differences would be found between the scores of mothers and fathers. This prediction was based on previous findings of researchers comparing posttraumatic growth scores of mothers and fathers of children who had died (Engelkemeyer & Marwit, 2008; Polatinsky & Espy, 2000).

Goal Two – Determine the relationship between demographic variables and posttraumatic growth scores for the full sample of parents as well as separately for groups of

mothers and fathers. Compare the relationship findings descriptively for similarities and differences that may exist between mothers and fathers.

With respect to the relationship between demographic factors and personal growth, I predicted that fathers' growth scores would be related to household income, employment status, and reports of how well the family is able to meet their needs with their current income. Through qualitative interviews, fathers shared that they often feel conflicted by their work and family obligations, resulting in feelings of exclusion and isolations (Clarke, 2005; Cook, 1984; Ware & Rival, 2007). Though Helgeson et al. (2006) found that benefit finding was unrelated to socioeconomic status, the above hypotheses were based on research showing that fathers of children with LTIs spend most of their energy thinking about and dealing with household and medical expenses (Brown & Barbarin, 1996). As such, I believed that factors related to income and employment would influence the beliefs these fathers have of themselves, which would in turn affect their reports of personal growth on the PTGI.

With respect to personal growth in mothers, I hypothesized that homemakers or those who experienced a change in family income because of their child's illness would have higher levels of growth on the scales of Relating to Others, New Possibilities, and Personal Strength, when compared to mothers working outside the home. In contrast to fathers, researchers have shown that mothers expend more energy tending to medical aspects of their child's illness and completing household chores (Brown & Barbarin, 1996). Women typically take on the role of primary caregiver (Berge et al., 2006; Brown & Barbarin; Morrod, 2004; Thompson, 2002), and as a result are more likely than fathers to have reduced their work hours or left a job completely. In taking on the role of full-time caregiver mothers may have had to abandon the pursuit of career-related goals set prior to their children's diagnosis. Thus, the above predictions were based on the assumption that through such life-changes mothers would have opportunities to realize inner strengths, build self-esteem, advocate for their child, and interact with others – experiences resulting in a sense of accomplishment and contributing to increased reports of personal growth.

Goal Three – Examine the personal growth scores within couple dyads in order to: a) explore the level of congruency that exists within the caregiving couple-dyads, and b) examine the extent that the score of one partner predicts the score of his or her partner.

Comparing the levels of congruency of all couples showed where the scores of couples fell with respect to one another. It was then determined if there was a difference between the proportion of couples where partners shared similar degrees of personal growth and couples that had opposite degrees of growth. Assessing the level of congruency in the data from couples is uncommon in research. Furthermore, there is a complete absence of congruency studies related to personal growth in couples. Based on research illustrating the influence that couples have on each others' overall adaptation and growth when a husband or wife has been diagnosed with an illness (Manne et al., 2004; Thornton & Perez, 2006; Weiss, 2004), I expected that more couples would have scores that were congruent to one another than couples who had incongruent scores. For example, if a mother had high posttraumatic growth scores, relative to the median scores for all mothers, her partner would also be likely to have high scores, relative to the median growth scores of all fathers.

Consistent with the above hypothesis related to congruency of couples' growth scores, I predicted that spouses/partners would have personal growth scores that were predictive of one another. The magnitude of predictability would vary across scales with the strongest effect being observed on the Relating to Others scale. This scale captures change in interpersonal relationships. This hypothesis was based on Manne, et al.'s (2006) research with couples that showed a relationship between growth and a communication style that allows for the expression and sharing of emotions, and the mutual discussion and resolution of issues.

Overview of Caregiving Parents Study Methodology

The current study was a secondary analysis. The data analysed were collected as part of a study entitled "Caregiving Parents of Children with Life-Limiting Illnesses: Beyond Stress and Coping to Growth (Cadell et al., 2006). Whereas the current study was concerned with how

couples experience personal growth, the intent of the Caregiving Parents Study was to enhance the understanding of individual factors that may affect positive outcomes in parents caring for a child with a life-limiting illness,

The Caregiving Parents Study used a cross-sectional survey to test personal growth in individuals who are caring for a child with a life-threatening illness. Parents volunteered for the study by responding to advertisements posted at various pediatric hospitals and care facilities across Canada and in the United States (Vancouver, Edmonton, Calgary, Toronto, Montreal, and San Francisco). Recruitment also took place through parent newsletters, local newspapers, and information letters that were sent directly to families through pediatric palliative care programs and parent organizations, such as Muscular Dystrophy Canada. Interested parents were prompted to call a toll-free number.

Eligible parents, who consented to participate, were assigned an identification code and mailed a questionnaire package (see Appendix A). Each package included a demographic survey designed by Stajduhar and Cohen (unpublished) and a series of questionnaires selected to ascertain information on personal resources (*Meaning in Caregiving Scale* [Giuliano, Mitchell, Clark, Harlow, & Rosenbloom, 1990], *Rosenberg's Self-Esteem Scale* [Rosenberg, 1965], and the *Life-Orientation Test-Revised* [Scheier, Carver, & Bridges, 1994]), spirituality (*Spirituality and Investment Beliefs Scale-Revised* [Hatch, Burg, Naberhaus, & Hellmich, 1998]), stressors (*The Center for Epidemiologic Studies Depression Scale* [Randolf, 1977], and a measure of burden [Pearlin, Mullen, Semple, & Skaff, 1990]) and personal growth (*Posttraumatic Growth Inventory* [Tedeschi & Calhoun, 1996]). Demographic information and data from the questionnaires were entered into a database for future analysis. Only data collected from the demographic survey and the Posttraumatic Growth Inventory were used in the current study.

Eligibility for Couples Study

The participants in the current study consisted of 34 couples ($N = 68$), who returned a questionnaire package from the Caregiving Parent Study prior to December 1, 2008. This number

represents 76% of the 45 couples mailed surveys as part of that study. In the remaining couples, either one or both parents did not return their questionnaire package. In addition to returning the questionnaire package, couples were considered eligible to participate if they met the following criteria: a) identified themselves as the parents of a child with a LTI, b) reported that they were currently married or living as married, and c) were cohabitating at the time they were recruited for the Caregiving Parent Study. Couples did not have to be the biological parents of the child.

Posttraumatic Growth Inventory

Personal growth perceptions were estimated using a slightly modified version of Tedeschi and Calhoun's (1996) Posttraumatic Growth Inventory (PTGI). For the Caregiving Parent Study the word "crisis" was changed to "as a result of your child's illness". A total growth score is derived from the PTGI, as well as five subscale scores: Relating to Others, New Possibilities, Personal Strength, Spiritual Change, and Appreciation of Life. The PTGI, which was developed to measure positive outcomes reported by persons who have experienced a traumatic event, asks participants to rate statements about changes in their lives as a result of their crisis (Tedeschi & Calhoun). Respondents rate 21-items using a 6-point Likert scale, ranging from 0 (*I did not experience this change*) to 5 (*I experienced this change to a very great degree*). Some examples of statements from the inventory include: *I have a greater willingness to share my emotions with others, I can better appreciate each day, I put more effort into my relationships*. A list of the items comprising each scale is given in Appendix B.

The scale was originally tested on a sample of 604 undergraduate students from a large university in the southeastern United States. The internal consistency of the resulting 21-item PTGI was $\alpha = .90$ with a test-retest reliability considered acceptable at $r = .71$ over two months (Tedeschi & Calhoun, 1996).

In response to an ongoing debate regarding the construct of growth, Taku, Cann, Calhoun, and Tedeschi (2008) recently examined the underlying structure of the PTGI using confirmatory factor analysis to test five proposed models. Their findings verified that the PTGI is

a multidimensional measure that captures five separate and meaningful factors, all correlated with growth. Thus, the five-factor structure of the PTGI is relatively robust and has good construct validity. This finding supports my decision to include the five subscale scores, in addition to the Total Growth score, in my analysis of the couples' data.

Procedures

Following ethical approval from Wilfrid Laurier University's Research Ethics Board, couples were identified through the Caregiving Parents database by examining identification codes. Codes consisted of two parts. The first part of the code being a family identification code and the second part representing his or her relationship to the child. For example, a biological mother and father of the same child would be assigned codes 25.1 and 25.2, respectively. This code indicates that they are both from the 25th family recruited, with .1 assigned to all mothers and .2 to all fathers. The demographic information for each member of a dyad was reviewed and cross-referenced with that of their partner, in order to confirm that they met the eligibility criteria set for a couple. The responses from the demographic survey and the Posttraumatic Growth Inventory of eligible dyads were then copied from the Caregiving Parents database and added to a separate Couples Study database constructed in Microsoft Office Excel 2007.

Each child was assigned to one of four illness categories depending on the prognosis of their LTI and available treatments. When information specific to an individual child was known this was also taken into account. These categories are based on the criteria outlined by ACT/RCPCH (2003). The criteria associated with the various categories serves as a guideline. There is no consensus on which LTIs fall into which category.

The number of categories used to collect information on community size, current income, employment status, and current occupation were collapsed into fewer groups due to the small number of participants originally represented in certain categories. Other categories were removed completely because they were not endorsed by any of the parents. For example, none of the participants reported their highest level of education to be less than some high school, and no

one reported that current income was totally inadequate to meet their needs. Although all couples were living together at the time they completed their surveys, there were cases where the responses given by couples did not match for size of the community, or the estimated current household income. These differences were minimized once categories were combined. Community size was compressed from 8 categories to 3, employment status from 8 to 5, and current income from 12 to 3.

Current or former occupation responses were condensed from seven categories into three: professional or management level positions, other full-time or part-time work outside the home, or homemaker. These more general categories allowed for responses specified by parents under the “other” category to be placed in an appropriate group. In order to assess differences between how well income meets needs and the PTGI scores of fathers, the group “not very well” was filtered out of the analysis because there was only one participant in this category. All demographic data used in analysis are presented in Tables 1 and 2.

Data Analysis

Analysis of data was conducted using SPSS version 16.0 statistical software package for Windows. Descriptive statistics were calculated for the full sample of parent caregivers, as well as separately for groups of mothers and fathers. Means, standard deviations, and ranges were calculated for demographic information that was measured at a continuous level. Frequencies and percentiles were calculated for categorical demographic information.

Total Growth score from the PTGI and the five subscale scores (Relating to Others, New Possibilities, Personal Strength, Spiritual Change, and Appreciation of Life) comprised the dependent variables throughout the various stages of data analysis across all three study goals. The level of measurement of PTGI scores was continuous. All tests performed were two-tailed with p -values compared to an alpha level of .05 to determine whether results were statistically significant. Effect sizes of significant relationships were calculated manually.

Goal One: Gender Differences in Post Traumatic Growth Scores.

The means and standard deviations of the PTGI scores were calculated along with the range of scores reported by mothers and fathers (Table 3). Paired samples t-tests were conducted to examine if there were any significant differences between the PTGI scores of mothers and fathers. Though it has been noted that personal growth scores of spouses/partners appear to be dependent upon one another in cases where one partner has been diagnosed with a serious illness (Manne et al., 2004; Thornton & Perez, 2006; Weiss, 2004), it is unknown if the same is true when couples are together caring for a child. While it is too soon to make assumptions about dependency in the current sample, analysis using paired data was chosen in order to control for, or partial off, the many factors shared by couples, such as socioeconomic status and family variables, thus strengthening the argument that differences found are due to gender (D. Hemsworth, personal communication, July 15, 2009). Paired samples t-tests were carried out for each of the six PTGI scores (Total Growth Score, Relating to Others, New Possibilities, Personal Strength, Spiritual Change, and Appreciation of Life).

Goal Two: Demographic Variables and Posttraumatic Growth Scores.

Demographic information collected from each partner served as the independent variables when assessing the relationship between selected factors and PTGI scores. Data from the survey measured at a continuous level was analysed in relation to PTGI scores using Pearson Correlation Testing. Pearson Correlation Testing was performed for the full sample of parents, as well as separately for groups of mothers and fathers. Analysing data separately for mothers and fathers allowed for descriptive comparisons to be made on the significant findings for each of the two groups.

The continuous independent variables included in the analysis were: the age of parent, age child, age of child at time of diagnosis, time since child's diagnosis, and the degree of difficulty in managing costs associated with caregiving and the child's illness (measured using a 10-point Likert scale). The analysis of the relationship between personal growth and a number of continuous demographic variables originally planned was abandoned due a lack of variability in

data collected or extreme ranges and inconsistencies in data reported. This included data collected on the number of children in the family, the number of unpaid caregivers, hours per week spent caregiving, and the amount of time volunteers provide support each week.

Categorical demographic variables and PTGI scores were analyzed using one-way between groups analysis of variance (ANOVA) when more than two categories were compared. Independent samples t-test were run when only two categories made-up the independent variable. Analysis was computed for the full sample, as well as by gender to allow for comparisons between mothers and fathers. Tukey's post hoc procedure was carried out to test for differences between specific categories.

Categorical independent variables included: size of community, highest level of education completed, employment status, current or former occupation, current household income, whether there has been a change in income as a result of a child's diagnosis, how well current income meets needs, importance of religion, and diagnostic category of child's illness. The relationship between ethnic background and PTGI scores was not analyzed because many parents gave multiple responses, others did not answer, did not know, or gave a response that could not be categorized as ethnicity, such as Caucasian.

Goal Three: Posttraumatic Growth Scores Within Couple-Dyads

The third goal of this study involved examining posttraumatic growth scores within couple-dyads. The first task was to examine personal growth scores within couples in order to compare the levels of congruency of all dyads. The congruence of PTGI scores for each couple were analyzed using a procedure outlined by Sterba et al. (2008). Each individual was labeled as having reported high or low degrees of growth. The labeling of individual scores was based on where his or her score fell in comparison to the median score calculated for each gender. Couples were then categorized manually into one of four conditions: both high, both low, mother high and father low, or mother low and father high. Once all couples were categorized, Chi-square

goodness of fit testing was performed to assess whether the proportion of couples falling within each category differed significantly across the four categories.

The four couple categories were then collapsed into two categories based on whether or not partners' scores were congruent. The two possible conditions that would define a couple as having congruent scores would be if the mother and father both had scores higher than their gender median, or the mother and father both had scores lower than their gender median. A couple belonging to the incongruent group would have scores that fell on opposite sides of their gender median score, i.e. the mother has a score above the female median and the father has a score below the male median, or vice versa. Chi-squared goodness of fit procedure was then repeated to test whether the proportion of couples having congruent scores differed significantly from the proportion of couples that had incongruent scores.

Following Chi square goodness of fit testing, simple linear regressions were conducted on scores of mothers and fathers for each of the six PTGI scores. This test was performed to examine the degree to which one partner's scores predicted the other. For this procedure maternal PTGI scores served as the independent variables and the dependent variables were paternal scores.

Chapter Five: Results

Descriptive Statistics of Sample

Means and ranges of parent age and demographic information pertaining to children are presented in Table 1, including the frequencies of each of the four diagnostic categories for the various life-threatening conditions reported. Information is given for the total sample of parents ($N = 68$), as well as separately for mothers and fathers. Independent samples t-test showed no significant difference between the mean age of the mothers and fathers, $t(66) = 1.05, p = .297$. The mean age of the ill children being cared for, age at diagnosis, and time since diagnosis varied slightly between the groups of mothers and fathers due to the timing of when questionnaires were returned to the research office and some variation in the dates given by partners for when a child was diagnosed.

Twenty-six of the couples who took part in the study ($n = 52, 76.5\%$) lived in Canada (six couples from each province of British Columbia, Alberta, Ontario, and Quebec, and one couple from each of Saskatchewan and Manitoba). The remaining eight couples ($n = 16$) were all from the United States and all resided in different states. Although country of residence and access to special care services were not variables analyzed in this study, stark contrasts were noted between the locations where Canadian and American couples reported accessing care for their children. For example, approximately 79% ($n = 41$) of Canadian parents reported accessing care through a hospital, whereas only 31% ($n = 5$) of American parents were receiving care for their child at a hospital. In contrast, the vast majority of American parents ($n = 13, 81.2\%$) received care at home for their child, compared to less than half of the Canadian parents ($n = 22, 42.3\%$).

Demographic information of parents collected using categories is presented in Table 2. Overall, the parents who took part in the current study were well educated and earned a good income. Half of the sample (50%) had a university undergraduate or post-graduate degree. Close to half of the individuals (47.1%) had an annual household income of \$100 000 or greater.

Table 1

Parent Age and Child Demographic Information for Full Sample and By Gender of Parent

	Total (<i>N</i> = 68) <i>M</i> (<i>SD</i>)	Mothers (<i>n</i> = 34) <i>M</i> (<i>SD</i>)	Fathers (<i>n</i> = 34) <i>M</i> (<i>SD</i>)
Age of Parent – years (SD) Range	42.82 (7.00) 26.98 - 57.69 yrs.	41.93 (6.51) 28.15 - 57.69 yrs.	43.72 (7.45) 26.98 - 57.02 yrs.
Gender of Child – <i>n</i> (%) Boys Girls	<i>N</i> = 34 14 (41%) 20 (59%)		
Age of Child – years (SD) Range	10.11 (5.05) 1.42 - 19.19 yrs.	10.10 (5.10) 1.42 - 19.19	10.12 (5.07) 1.47 - 19.19
Age of Child at Diagnosis – years (SD) Range	2.83 (2.97) 0.00 - 11.22 yrs.	2.92 (2.10) .00 - 11.22	2.74 (2.99) .00 - 11.15
Time Since Diagnosis – years (SD) Range	7.31 (5.31) 0.45 - 19.16 yrs.	7.24 (5.37) .45 - 19.16	7.38 (5.32) .45 - 19.16
Diagnostic Category Cure available Treatment to extend life expectancy Progressive illness, treatment palliative Severe neurological disease, non-progressive, no cure	<i>N</i> = 34 5 (14.7%) 4 (11.8%) 18 (52.9%) 7 (20.6%)		

Many of the participants currently or formerly held management level or professional positions. As shown in Table 2, nearly as many mothers were employed full-time (*n* = 12) as were unemployed (*n* = 10). This observation is in stark contrast to the employment statuses endorsed by fathers. Almost all fathers (32 out of 33 respondents) indicated that they were employed full-time. The majority of mothers and fathers (77.6%) identified themselves as Christian, with approximately 18% (*n* = 12) responding “none” or not specifying any religious affiliation.

Table 2

Categorical Demographic Information for Mothers and Fathers

	Total <i>N</i> (%)	Mothers <i>n</i> (%)	Fathers <i>n</i> (%)
Community Size (population)	<i>N</i> = 68	<i>n</i> = 34	<i>n</i> = 34
Metropolitan or Large City (≥ 100 000)	31 (45.6)	15 (44.1)	16 (47.1)
Medium or Small City (10 000 to 99 999)	21 (30.9)	11 (32.4)	10 (29.4)
Town or Village (≤ 9 999)	16 (23.5)	8 (23.5)	8 (23.5)
Highest Level of Education			
Some High School	3 (4.4)	1 (2.9)	2 (5.9)
High School Diploma	7 (10.3)	5 (14.7)	2 (5.9)
Some College/CEGEP	8 (11.8)	4 (11.8)	4 (11.8)
College Diploma/Trade	10 (14.7)	4 (11.8)	6 (17.6)
Attended university	6 (8.8)	2 (5.9)	4 (11.8)
University Degree	18 (26.5)	7 (20.6)	11 (32.4)
Post Graduate Degree	16 (23.5)	11 (32.4)	5 (14.7)
Employment Status	<i>N</i> = 67	<i>n</i> = 34	<i>n</i> = 33
Full-time	44 (65.7)	12 (35.3)	32 (97.0)
Part-time	7 (10.4)	6 (17.6)	1 (3.0)
Self-employed	3 (4.5)	3 (8.8)	
Not employed	10 (14.9)	10 (29.4)	
Other	3 (4.5)	3 (8.8)	
Current or Former Occupation	<i>N</i> = 68	<i>n</i> = 34	<i>n</i> = 34
Professional or management	40 (58.8)	16 (47.0)	24 (70.6)
Other out of home work (full or part time)	20 (29.4)	11 (32.3)	9 (26.5)
Homemaker	8 (11.8)	7 (20.6)	1 (2.9)
Household Income (before taxes)	<i>N</i> = 66	<i>n</i> = 34	<i>n</i> = 32
Low (≤\$49,999/year)	7 (10.3)	4 (11.8)	3 (8.8)
Medium (\$50,000 to 99,999/year)	27 (39.7)	16 (47.1)	11 (32.4)
High (≥\$100,000/year)	32 (47.1)	14 (41.2)	18 (52.9)
Change in family income as a result of child's diagnosis	<i>N</i> = 67	<i>n</i> = 33	<i>n</i> = 34
Yes	37 (55.2)	21 (63.6)	16 (47.0)
No	30 (44.8)	12 (36.4)	18 (52.9)
How well current income meets needs?	<i>N</i> = 67	<i>n</i> = 33	<i>n</i> = 34
Completely	5 (7.5)	2 (6.1)	3 (8.8)
Very well	13 (19.4)	5 (15.2)	8 (23.5)
Adequately	25 (37.3)	12 (36.4)	13 (38.2)
With some difficulty	20 (29.9)	11 (33.3)	9 (26.5)
Not very well	4 (6.0)	3 (9.1)	1 (2.9)
Importance of Religion	<i>N</i> = 68	<i>n</i> = 34	<i>n</i> = 34
Very important	26 (38.2)	14 (41.2)	12 (35.3)
Of medium importance	16 (23.5)	6 (17.6)	10 (29.4)
Of little importance	18 (26.4)	10 (29.4)	8 (23.5)
Not at all important	8 (11.8)	4 (11.8)	4 (11.8)

Goal One: Gender Differences in Posttraumatic Growth Scores

As shown in Table 3, the post-traumatic growth scores of mothers were higher than those of the fathers on all scales of the PTGI. Paired samples t-test indicated that mothers had significantly higher Total Growth scores than fathers, $t(33) = 2.04, p = .049$. The actual differences between the mean Total Growth scores of gender groups was small, $d = 0.35$.

The differences in mean scores of mothers and fathers on the five subscales of Relating to Others ($t(33) = 1.86, p = .072$), New Possibilities ($t(33) = 1.60, p = .120$), Personal Strength ($t(33) = 1.36, p = .183$), Spiritual Change ($t(33) = 1.71, p = .097$) and Appreciation of Life ($t(33) = .94, p = .355$) were not significant.

Total Growth scores and standard deviations calculated for mothers and fathers were within the range of those reported in previous research using the PTGI (see Linley & Joseph, 2004, Table 1). Table 3 illustrates the considerable overlap found in the range of scores reported by mothers and fathers on each of the PTGI scales in the current study.

Goal Two: Demographic Variables and Posttraumatic Growth Scores

Investigation of the relationship between demographic variables and participants' personal growth revealed a number of significant relationships. While some of these findings were only evident when analysis was carried out for the full sample of parents, other significant findings illustrated differences and similarities between the groups of mothers and fathers.

Full Sample Analysis of Continuous Demographic Variables.

Significant relationships were found between age of the parent and all six scales of the PTGI. All relationships were negative, indicating that younger parents reported greater growth. Medium effect sizes were found for relationships between age and scores on the scales of Total Growth, $r(66) = -.38, p = .001$, Relating to Others, $r(66) = -.37, p = .002$, New Possibilities, $r(66) = -.363, p = .002$, and Spiritual Change, $r(66) = -.36, p = .003$. The relationships between age of parent and scores on the scales of Personal Strength, $r(66) = -.24, p = .047$, and Appreciation of Life, $r(66) = -.25, p = .043$, had small effect sizes.

Table 3

Means and Ranges of Post-Traumatic Growth Inventory Total Growth and Scale Scores for Mothers and Fathers Caring for a Child with a Life-Threatening Illness

	Total Growth Mean (SD)	Relating to Others Mean (SD)	New Possibilities Mean (SD)	Personal Strength Mean (SD)	Spiritual Change Mean (SD)	Appreciation of Life Mean (SD)
Mothers Range	61.12 (18.65)* 22 - 104	20.62 (7.53) 6 - 35	14.79 (4.75) 4 - 25	12.79 (4.29) 5 - 20	4.26 (3.36) 0 - 10	10.24 (3.52) 1 - 15
Fathers Range	52.65 (21.64)* 13 - 101	18.09 (8.06) 1 - 34	12.91 (5.59) 4 - 25	11.41 (4.80) 0 - 20	3.09 (3.73) 0 - 10	9.50 (3.06) 2 - 15
Full Sample Range	56.88 (20.50) 13 - 104	19.35 (7.84) 1 - 35	13.85 (5.24) 4 - 25	12.10 (4.57) 0 - 20	3.68 (3.57) 0 - 10	9.87 (3.30) 1 - 15
Scale Range.	0 - 105	0 - 35	0 - 25	0 - 20	0 - 10	0 - 15

* $p < .05$

Significant relationships were also found between age of child and PTGI scores on the scales of Total Growth, $r(66) = -.26, p = .030$, and Relating to Others, $r(66) = -.33, p = .007$. The relationship between age of child and scores on the New Possibilities scale approached significance, $r(66) = -.24, p = .051$. The negative direction of these correlations shows that those with younger children had higher scores. The effect sizes of the relationships were small for scores on The Total Growth and New Possibilities scales. The relationship between scores on the Relating to Others scale and age of child was of medium magnitude.

While there were no significant relationships found between age at diagnosis and growth scores of parents, time since diagnosis was significantly related to scores on the Relating to Others scale, $r(66) = -.28, p = .023$. However, the effect size of this relationship was small. The negative correlation indicates that scores were higher for those whose children had received a diagnosis of an LTI more recently.

Scores on the Relating to Others scale were also significantly correlated with participants' responses to the degree of difficulty managing costs associated with caregiving, with 1 being "not at all difficult" and 10 being "very difficult". The significant negative relationship, $r(62) = -.25, p = .042$, demonstrates that parents who find it more difficult to manage expenses have lower growth scores on the Relating to Others scale. The strength of this relationship was of medium magnitude.

Comparison of Mothers and Fathers for Continuous Demographic Variables.

When the data file was split by gender of parent the degree of difficulty managing caregiving costs was no longer significantly related to PTGI scores for mothers or fathers. None of the above mentioned relationships from the full sample analysis remained when the scores of mothers were examined separately. That is, there were no significant relationships found between age of parent or age of child, age of child at diagnosis, or time since diagnosis and the personal growth scores of mothers.

Relationships between the age of parent and the age of child and personal growth scores did remain significant for the group of fathers. The age of fathers was found to be negatively correlated with Total Growth, $r(66) = -.48, p = .004$, and scores on the scales of Relating to Others, $r(66) = -.44, p = .010$, New Possibilities, $r(66) = -.39, p = .023$, and Spiritual Change, $r(66) = -.54, p = .001$. All relationships were of a medium magnitude, with the exception of the relationship between age of parent and Spiritual Change, which was large. A significant relationship, that was of medium magnitude and negative in direction, was found for age of child and paternal scores on the PTGI scales of Total Growth, $r(66) = -.35, p = .045$, Relating to Others, $r(66) = -.37, p = .030$, and Spiritual Change, $r(66) = -.40, p = .018$. The variable of time since diagnosis was on the cusp of being significantly related to scores on the Relating to Others scale for fathers, $r(66) = -.33, p = .058$, and was also of medium magnitude.

Categorical Variables and Personal Growth – Non-Significant Findings.

No significant differences were found in the full sample of parents or when tested separately for groups of mothers and fathers for the demographic variables of highest level of education, employment status, household income, having experienced a change in family income as a result of the child's diagnosis, or how well income meets needs.

Though it was hypothesized that employment status of fathers would be related to PTGI score of fathers, analysis could not be carried out to test for differences because only the full-time group had more than one member. The absence of a relationship between the personal growth scores of fathers and their reports of household income contradicted what had been hypothesized. The hypothesis that mothers who had experienced a change in family income would experience more growth was also not supported.

How well income meets needs – Post Hoc Results.

Though it is not an accepted procedure to run post hoc analysis when ANOVA does not show significant between group differences, learning this was part of my learning curve in analyzing quantitative data. As a result, post hoc testing was conducted simultaneously with ANOVA testing.

Post hoc analysis provided some support for the hypothesis that fathers' personal growth would be related to reports of how well current income met needs. Although between-group differences for how well current income meets needs and PTGI scores were not significant for the full sample of parents or for either gender group, Tukey's HSD post hoc analysis showed there to be significant differences between those who gave certain responses. Significant differences in the Relating to Others scores of fathers were found between those who reported their needs were being met "very well" ($M = 24.50, SD = 7.23$) and fathers who answered with "adequately" ($M = 15.00, SD = 5.90$), $p = .044$. Similarly, there were significant differences between the Relating to Others scores of mothers who reported that their needs were met "completely" by their current income ($M = 31.00, SD = 1.41$), compared to those who responded that needs were being not

being met very well ($M = 13.33$, $SD = 10.21$), $p = .048$. These results should be interpreted with caution as the number of mothers in these two groups were small, two and three respectively.

Community Size Full Sample.

Community size was found to have a large significant effect on scores on the Relating to Others scale, $F(2,65) = 5.28$, $p = .007$, $\eta^2 = .14$. Tukey's HSD post hoc procedure indicated that parents residing in medium or small cities ($M = 23.43$, $SD = 6.15$) had scores on the Relating to Others scale that were significantly higher than those living in metropolitan areas or large cities ($M = 18.42$, $SD = 8.17$, $p = .050$), as well as those residing in towns or villages ($M = 15.81$, $SD = 7.25$, $p = .008$).

Community Size Compared by Gender.

Analysis by gender found that community size accounted for 42% of the variance in the scores of mothers on the Relating to Others scale, $F(2, 31) = 6.47$, $p = .004$, $\eta^2 = .417$. The scores of mothers living in medium or small cities ($M = 25.82$, $SD = 4.94$) were significantly higher than those of mothers living in towns or villages ($M = 15.12$, $SD = 6.85$), $p = .004$. The Levene test showed homogeneity of variance among the groups.

No significant relationships were found for the community size of fathers' and PTGI scores.

Current or Former Occupation Full Sample.

For the full sample of parents no significant differences were found between PTGI scores of the three current or former occupation groups (management or professional level position, other full-time or part-time work outside the home, or homemaker).

Current or Former Occupation Compared by Gender.

When ANOVA was performed separately for the group of mothers, significant differences were found between current or former occupation and Total Growth scores, $F(2,31) = 3.36$, $p = .048$, as well scores on the Spiritual Change scale, $F(2,31) = 5.58$, $p = .009$. The

difference in mean Total Growth scores between the three groups was large, $\eta^2 = .18$, with the difference in mean Spiritual Change scores between the groups being very large, $\eta^2 = .26$.

Post hoc comparisons using Tukey HSD test indicated that mean Total Growth scores of mothers who worked full-time or part-time outside the home ($M = 71.82$, $SD = 19.91$) was on the cusp of being significantly higher than the mean score of mothers who were homemakers ($M = 51.71$, $SD = 19.02$), $p = .059$. Post hoc comparisons also showed that the mean scores on the Spiritual Change scale were significantly higher for mothers currently or formerly employed in non-professional or non-management roles outside the home ($M = 6.64$, $SD = 2.66$) compared to those who were employed in these positions ($M = 3.50$, $SD = 3.22$, $p = .030$) and compared to homemakers ($M = 2.29$, $SD = 2.81$, $p = .013$).

Because only one father identified himself as a homemaker, independent samples t-test was conducted to test for differences between fathers whose current or former occupation was professional/management compared to other occupations outside the home. No significant differences were found between PTGI scores for these two groups.

Importance of Religion for Full Sample.

Analysis of the full sample of parents using the four response categories to the question “How important is religion to you?” showed significant between group differences on the Total Growth scale, $F(3, 64) = 3.24$, $p = .028$, $\eta^2 = .132$, and Spiritual Change scale, $F(3, 64) = 16.53$, $p < .001$, $\eta^2 = .437$. While, the Levene test showed homogeneity of variance among the groups for the Total Growth scale, $p = .45$, this was not the case among the groups for the Spiritual Change scale, $p = .012$. Tukey’s HSD post hoc procedure showed Total Growth scores of those who responded that religion was “very important” ($M = 66.00$, $SD = 21.42$) were significantly higher than those who identified religion to be of medium importance ($M = 48.81$, $SD = 18.30$, $p = .036$).

Due to the lack of homogeneity across the four groups on the Spiritual Change scale and the unexpected finding that significant differences in Total Growth existed only between those who felt religion was very important and those who viewed it as being of medium importance,

further analysis of this variable was performed. Groups were collapsed into two categories to examine differences in the mean scores of the 26 parents who responded that religion was “very important” compared to those who did not. That is, the comparison group consisted of 42 individuals who reported religion to be of medium or little importance, or not at all important. For the full sample of parents significant differences were found between the scores of these two groups on Total Growth, $t(66) = 3.06, p = .003, d = .76$, and the scales of Relating to Others, $t(66) = 2.08, p = .041, d = .52$, Personal Strength, $t(66) = 2.21, p = .031, d = .55$, and Spiritual Change, $t(66) = 6.68, p < .001, d = 1.54$. Whereas actual differences in mean scores on the Spiritual Change scale were very large, the effect size of differences on Total Growth, Relating to Others, and Personal Strength were moderate.

Importance of Religion Comparison by Gender (Four Categories).

For the sample of mothers, significant between group differences were found in Spiritual Change scores, $F(3, 30) = 4.833, p = .007$ when the four levels of importance were compared (very important, of medium importance, of little importance, not at all important). The eta-square value of $\eta^2 = .370$ indicates that importance of religion accounted for 37% of the variance in the Spiritual Change scores of mothers. Tukey’s post hoc comparisons identified significant differences between mothers who reported religion to be very important ($M = 6.29, SD = 3.41$) and the group who responded that it was of little importance ($M = 2.30, SD = 2.54, p = .012$) or not at all important ($M = 1.75, SD = 2.87, p = .045$). Homogeneity of variance was shown to exist among the groups, $p = .250$.

For fathers, importance of religion was significantly related to differences in mean Total Growth scores, $F(3, 30) = 3.85, p = .019$. The large effect size of $\eta^2 = .278$ indicates that 28% of variance in the Total Growth scores of fathers was accounted for by the importance of religion. Importance of religion accounted for 60% of the variance in the Spiritual Change scores of fathers, $F(3, 30) = 15.22, p < .001, \eta^2 = .603$. Fathers who reported religion was very important had significantly higher scores ($M = 6.83, SD = 3.43$) compared to those who responded that it

was of medium importance ($M = 2.00, SD = 2.36, p < .001$), of little importance ($M = .25, SD = .46, p < .001$), or not at all important ($M = .25, SD = .50, p < .001$). However, the Levene test showed that homogeneity of variance was not present among the four groups for fathers for Spiritual Change scores, $p = .003$.

Importance of Religion Comparison by Gender (Two Categories).

When divided into two importance of religion categories (group 1: very important and group 2: medium/little/ not at all important) the mean Spiritual Change score of the 14 mothers in group one ($M = 6.29, SD = 3.41$) was significantly higher than the mean score of the 20 mothers in the second group ($M = 2.85, SD = 2.56$), $t(32) = 3.363, p = .002$. The magnitude of this difference was found to be very large, $d = 1.17$.

The 12 fathers who responded that religion was very important had significantly higher mean scores than their counterparts who reported religion to be of medium importance, little importance, or not at all important on Total Growth ($M = 67.50, SD = 20.66$ versus $M = 44.55, SD = 17.82$), $t(32) = 1.94, p = .002, d = 1.22$, and the scales of New Possibilities ($M = 15.83, SD = 5.42$ versus $M = 11.32, SD = 5.12$), $t(66) = 2.407, p = .022, d = .86$, Spiritual Change ($M = 3.43, SD = 0.99$ versus $M = 1.01, SD = 1.81$), $t(32) = 5.44, p < .001, d = 1.95$, and Appreciation of Life ($M = 11.25, SD = 2.83$ versus $M = 8.55, SD = 2.79$), $t(32) = 2.69, p = .011, d = .96$. Differences on the Relating to Others scale also approached significance ($M = 21.58, SD = 7.54$ versus $M = 16.18, SD = 7.85$), $t(32) = 1.94, p = .061, d = .70$. Calculations showed the effect size of these differences to be in the large or very large range, based on Cohen's guidelines, with the exception of differences on the Relating to Others scale, which was of medium magnitude.

Diagnostic Category of Child's Illness Full Sample.

For the full sample of parents, there were no significant differences between mean PTGI scores of the four diagnostic category groups of child's illnesses (cure available, treatment available to extend life expectancy, progressive with no cure/treatment palliative, severe

Table 4

Means and Standard Deviations of Posttraumatic Growth Inventory Scores for Full Sample of Parents by Diagnostic Category of Child's Illness

	Total Growth Mean (SD)	Relating to Others Mean (SD)	New Possibilities Mean (SD)	Personal Strength Mean (SD)	Spiritual Change Mean (SD)	Appreciation of Life Mean (SD)
Cure available	60.50 (18.36)	24.00 (6.00)*	15.20 (4.34)	12.00 (4.83)	3.70 (3.95)	11.50 (3.44)*
Treatment to extend life expectancy	58.00 (18.34)	19.00 (6.74)	14.50 (5.24)	13.50 (3.30)	4.75 (3.20)	10.00 (.926)
Progressive/ Treatment palliative	54.25 (19.89)	18.08 (8.05)*	13.36 (5.11)	11.47 (4.74)	3.08 (3.32)	9.39 (3.02)*
Severe neurological/Non- progressive	60.43 (25.34)	19.50 (8.50)	13.79 (6.40)	13.00 (4.71)	4.57 (4.15)	9.86 (4.49)

* $p < .05$

neurological/ non-progressive condition). Although differences were not significant, the scores of parents of children with progressive conditions, for which treatment is palliative and there is no cure, had the lowest mean scores on Total Growth and all five subscales of the PTGI. Mean scores and standard deviations of the four groups are shown in Table 4.

Diagnostic Category of Child's Illness Compared by Gender.

Examination of PTGI scores for mothers only showed that mothers of children with progressive conditions reported the lowest growth on all six measures, as shown in Table 5. Differences in mean scores reached significance on the scales of Relating to Others and Appreciation of Life. Post hoc comparisons of the Relating to Others scale indicated that the mean score of mothers of children with progressive illnesses was significantly lower than those who have children with a potentially curable condition, $p = .039$. Significant differences also existed between these same two groups of mothers on the Appreciation of Life scale. Mothers of children with progressive illnesses again had significantly lower scores, $p = .044$.

Table 5

Means and Standard Deviations of Posttraumatic Growth Inventory Scores for Mothers by Diagnostic Category of Child's Illness

	Total Growth Mean (SD)	Relating to Others Mean (SD)	New Possibilities Mean (SD)	Personal Strength Mean (SD)	Spiritual Change Mean (SD)	Appreciation of Life Mean (SD)
Cure available	72.80 (14.41)	27.80 (5.22)*	18.80 (1.64)	14.60 (5.03)	4.60 (4.04)	14.00 (1.00)*
Treatment to extend life expectancy	65.00 (18.22)	21.25 (5.62)	16.25 (4.86)	14.00 (3.56)	6.00 (1.63)	10.25 (.50)
Progressive/ Treatment palliative	55.94 (16.17)	17.83 (7.47)*	13.61 (4.10)	11.83 (3.92)	3.44 (3.11)	9.39 (3.38)*
Severe neurological/Non- progressive	63.86 (25.60)	22.29 (7.06)	14.14 (6.59)	13.29 (5.28)	5.14 (4.18)	9.71 (4.57)

* $p < .05$

For the group of mothers, between group differences in mean scores of the four illness categories approached significance on the Relating to Others scale, $F(3, 30) = 2.88, p = .052, \eta^2 = .22$, and the Appreciation of Life scale, $F(3, 30) = 2.64, p = .068, \eta^2 = .21$, both with a small effect size.

For fathers only, there were no significant differences found between the four child diagnostic categories and PTGI scores. In contrast to what was noted when the mean scores of the four groups of mothers were compared, it was fathers of children who were diagnosed with potentially curable conditions who had the lowest mean scores overall on Total Growth and the scales of New Possibilities, Personal Strength, and Appreciation of Life. None of these differences were significant.

Goal Three: Posttraumatic Growth Scores Within Couple-Dyads

Congruency of Couple's Scores.

There were no significant differences between the proportion of couples fitting into four categories of both partners having high scores relative to their gender median scores, both having low scores, mother high and father low, and mother low and father high on either the Total Growth scale, $X^2(3, N = 34) = 0.12, p = .990$, or the five scales of Relating to Others, $X^2(3, N = 34) = 3.18, p = .365$, New Possibilities, $X^2(3, N = 34) = 1.06, p = .797$, Personal Strength, $X^2(3, N = 34) = 1.06, p = .787$, Spiritual Change, $X^2(3, N = 34) = 1.53, p = .675$, and Appreciation of Life, $X^2(3, N = 34) = 2.94, p = .401$.

Contrary to what was hypothesized, results of chi-squared goodness of fit testing once again revealed no significant differences between the proportion of couples with congruent scores (both partners having either high or low scores relative to their gender median scores) compared to incongruent scores on either the Total Growth scale, $X^2(1, N = 34) = 0.12, p = .732$, or the five scales of Relating to Others, $X^2(1, N = 34) = 2.94, p = .086$, New Possibilities, $X^2(1, N = 34) = 1.06, p = .303$, Personal Strength, $X^2(1, N = 34) = 0.00, p = 1.00$, Spiritual Change, $X^2(1, N = 34) = 1.06, p = .303$, and Appreciation of Life, $X^2(1, N = 34) = 1.06, p = .303$. The greatest difference between the proportion congruent and incongruent couples was observed on the Relating to Others scale. On this scale 22 couples had scores that were congruent compared to 12 couples who had incongruent scores.

Simple Linear Regression.

The growth scores of mothers were a significant predictor of fathers' scores on the Relating to Others scale, $\beta = .48, t(33) = 3.12, p = .004$. As shown in Table 6, mothers' scores had a large effect on the Relating to Others scores of fathers, accounting for 23% of variance. Maternal scores were also a significant predictor of fathers scores on the Spiritual Change scale, $\beta = .36, t(33) = 2.19, p = .036$, accounting for 13% of variance in the Spiritual Change scores of fathers. Mothers' scores were the least predictive of fathers' Appreciation of Life scores.

Table 6

*Regression Analysis with Mother's Posttraumatic Growth Inventory Scores as Predictor Variable
of Father's Posttraumatic Growth Inventory Scores*

	Total Growth	Relating to Others	New Possibilities	Personal Strength	Spiritual Change	Appreciation of Life
R square	.081	.233**	.015	.023	.130*	.002

* $p < .05$

** $p < .01$

Chapter Six: Discussion

The current study is a secondary analysis of data reported by 34 couples ($N = 68$) who were together actively caring for a child with a life-threatening illness (LTI). The couples who volunteered for the study were from across Canada and the United States and were caring for children with a variety of conditions, all of which are considered life-threatening.

The current investigation has been conducted to gain an appreciation of the potential for positive outcomes in couples who have a child with a LTI. Specifically, the purpose of this quantitative study is to examine reports of personal growth in couples, with a focus on the differences and similarities that may exist between groups of mothers and fathers and within couple-dyads. The study is also concerned with demographic factors that may potentially influence growth in parents. There are three overarching goals of this research: (a) to test for differences in personal growth scores of mothers and fathers, as measured by the Posttraumatic Growth Inventory ([PTGI] Tedeschi & Calhoun, 1996), (b) to investigate the influence of demographic variables on personal growth in parent caregivers and describe similarities and differences that exist between mothers and fathers, (c) to examine personal growth scores within couple-dyads to test for levels of congruency (thereby addressing the question of whether partners are more or less likely to have scores that are similar to one another, relative to their median gender scores), as well as the degree to which personal growth scores of partners are predictive of one another.

A growing recognition that loss, grief, and various forms of life struggles can lead to positive transformations has led to a growing body of literature documenting the occurrence of personal growth (Barakat et al., 2006, Cadell, 2007; Cadell et al., 2003; Cheng, et al., 2006; Hogan & Schmidt, 2002; King & Patterson, 2000; Manne et al., 2004; Polatinsky & Esprey, 2000; Riley et al., 2007; Thornton & Perez, 2006; Weiss, 2004). Prior to the current study, couples caring for a child with a LTI were not represented in the personal growth literature.

Examining the experience of couples provides a number of unique opportunities to investigate differences and make comparisons in personal growth of women and men, as well as potential factors that contribute to growth in couples. One issue that complicates attempts to draw conclusions about gender differences in personal growth is that reports are often confounded by the nature of events investigated (Helgeson et al., 2006). Having a sample consisting exclusively of couples allows direct comparisons to be made between women and men who have all experienced the same crisis of having a child diagnosed with a LTI. The couples in the study have all experienced the range of emotions, struggles, and triumphs that come with providing care for their children. Thus, having this homogenous sample eliminates the challenge of attempting to draw conclusions about gender when individuals do not share a common trauma or life crisis. Having a sample of couples allows for comparisons to be made using analysis methods that parcel out variables typically shared by the couples, such as socioeconomic status, age range, and family characteristics. In so doing, the claim that differences found are related strictly to gender is strengthened.

Results of the current study show that mothers had significantly higher Total Growth scores than the fathers. This finding contradicts what was hypothesized and provides some support for Tedeschi and Calhoun's (1996) early claim that women exhibit greater growth. Compared to the PTGI scores of fathers, mothers showed greater growth on the scales of Relating to Others, New Possibilities, Personal Strength, Spiritual Change, and Appreciation of Life, though not to a significant degree. These findings are consistent with those of researchers who explored personal growth in mothers and fathers who had experienced the death of their child (Engelkemeyer & Marwit, 2008; Polatinsky & Esprey, 2000). It is speculated that a reason why gender differences are significant on the Total Growth scale and not on any of the five subscales may be due to restricted range of scores generated by each subscale (see Table 3). The limited range in scores, due to the number of items contributing to each scale, makes it challenging to obtain significant results when making comparisons across groups. The range of scores of

mothers and fathers on the six PTGI measures illustrates the high degree of overlap that is present when comparing personal growth across genders.

Similar to past investigations of gender differences, examinations of factors that may moderate growth have generated mixed results. The current study examines the relationship between demographic variables and personal growth in the full sample of parent caregivers, as well as separately for groups of mothers and fathers. This approach allows comparisons to be made between the similarities and differences in factors that may prove to be influential to the growth of women and men. The extensive list of demographic variables analyzed in relation to PTGI scores in the current study are outlined in Tables 1 and 2.

Results show that younger parents reported significantly more growth in all areas measured by the PTGI, including interpersonal relationships, identification of personal strengths and new opportunities, an appreciation of life, and spiritual change. These results are consistent with Helgeson et al.'s (2006) meta-analysis showing younger age to be associated with greater benefit finding. Manne et al. (2004) found young breast cancer patients to have higher growth scores than older women. The researchers suggested that younger patients may be more conscious of the cultural expectation to adopt a positive attitude and may be more motivated to do so.

When gender groups were compared, younger fathers, but not mothers, had higher scores in the areas of Total Growth, Relating to Others, New Possibilities, Spiritual Change, and Appreciation of Life. It is speculated that this generational gap may be related to younger fathers taking on more responsibilities in providing care for their dying children, which may lead to a realization of strengths and a re-evaluation of one's outlook on life. Perhaps age-related findings are representative of a generational shift, whereby younger fathers have become more engaged or directly involved in family dynamics. That being said, a parent's level of growth should not be interpreted as a reflection of commitment to his or her family or child.

Anderson and Lopez-Baez (2008) measured growth in 351 full-time college students and found scores to be within the range of those reported by researchers studying growth following

trauma or life crisis. The researchers propose that growth is a developmental process and the consequence of both negative and positive life experiences. Cadell and Sullivan (2006) also consider that posttraumatic growth seen in bereaved caregivers may be part of a developmental process. They suggest that through the resolution of grief, growth may take place outside of the normal time course of life, serving an adaptive function in the midst of crisis. As such, higher growth in younger fathers in the current study may be related to a combination of their current life stage, family situation, and the accumulation of past experiences. As men become immersed in the roles of father, husband, and caregiver they may recognize the importance of building and nurturing relationships with others. During this time they may have opportunities to take part in experiences not known to them previously, and gain an overall appreciation for the joys of life and what the future holds for them and their new families. The fact that fathers with younger children show significantly greater overall growth (Total Growth), as well as interpersonal relationship growth (Relating to Others), speaks to the transformation that may take place in new fathers.

The relationship between community size and personal growth has not been previously documented in the literature. Opportunities to become part of a supportive social network may be one reason why parents living in medium and small cities experience more growth in the area of interpersonal relationships than those living in larger cities or in smaller towns. Large differences are noted between the Relating to Others scores of these three groups. Residing in towns or villages may not afford parents the opportunities to engage with professionals or other parents. Caregivers living in large cities may be close to services, but not experience the same sense of community as those living in smaller cities.

For mothers, community size accounts for 42% of the variance in Relating to Others scores. No differences are noted in reported personal growth of fathers living in different size communities. Perhaps this discrepancy is because fathers do not seek out support in their

communities to the same extent as mothers. Men may find support from sources other than neighbours, such as through work colleagues, friends or family.

Current or former occupation appears to be a second factor not previously examined in relation to personal growth. Occupation is not related to personal growth for the full sample of parents or for fathers. For mothers, large differences in overall growth and very large differences in spiritual change are identified between those who reported their current or former occupation to be in a professional or management level position, other full-time or part-time occupations outside the home, and homemakers. Mothers whose current or former occupation involved work outside the home in positions such as clerical or manual labour had significantly higher Total Growth and Spiritual Change scores, and also had the highest scores on the remaining four scales of Relating to Others, New Possibilities, Personal Strength, and Appreciation of Life. These findings appear to contradict the hypothesis that mothers who are homemakers would report the highest levels. While results in the area of occupation are relevant for mothers who may consider giving up their occupation, findings highlight the influence that type of employment may have on a mother's well-being. In the current sample of mothers almost as many women were unemployed as employed full-time. No significant relationship was found between the employment status of mothers and personal growth.

Personal growth of fathers was not directly related to household income, in contrast to what was hypothesized. However, an association was revealed between how well income meets needs and interpersonal relationship growth. For both fathers and mothers those who found it relatively easier to meet needs had higher scores in this area. Similarly, parents who reported less difficulty managing costs associated with medical expenses and their child's illness had significantly higher scores on the Relating to Others scale. It appears that the stress that comes with worrying about and managing expenses may impede opportunities to develop or maintain relationships. Having a strong support system of peers, family members, and service providers

may dissipate some of the financial burden that parents with fewer supportive relationships experience.

Importance of religion was associated with the personal growth of parents across multiple areas. Parents who reported religion to be very important had greater overall growth, as well as higher levels of growth on the areas of interpersonal relationships, recognition of personal strength, and spiritual change when compared to those who endorsed religion as being of medium, little, or not at all important. While the only significant difference for mothers was on mean scores of Spiritual Change, fathers who reported that religion was very important had significantly higher reports of growth on the scales of Total Growth, New Possibilities, Spiritual Change, and Appreciation of Life. These results are consistent with those documented in meta-analysis of benefit finding research showing positive associations between growth and religiosity (Helgeson et al., 2006). Scores on a measure of spirituality were positively correlated with growth in a group of bereaved caregivers and proved to be the single best predictor of PTGI scores (Cadell & Sullivan, 2006). While those working in a health care setting may be uncomfortable raising the issue of spirituality, this finding speaks to the importance of acknowledging the potential role that spirituality may have for parents confronted with a child's medical crisis or disability.

The child of each couple in the study was allocated to a diagnostic category based on the available treatment and prognosis of his or her illness. Parents of children with progressive illnesses for which there are currently no known cures have the lowest levels of personal growth across all areas assessed, though differences were not significant. While this pattern of relatively low scores in the progressive illness group remains when scores of mothers are examined, it was interesting to note that fathers of children with potentially curable conditions actually have the lowest mean scores on Total Growth and the scales of New Possibilities, Personal Strength, and Appreciation of Life. None of these differences are significant.

For mothers, diagnostic category of a child's illness was modestly related to reports of growth on the Relating to Others and Appreciation of Life scale, accounting for 22% and 21% of the variance in these scores, respectively. Mothers of children with a potentially curable conditions had significantly higher scores than mothers of children with progressive illness on both of these scales. The idea that severity of a child's illness can influence the well-being of parents is supported by previous research that documented that families had lower perceptions of cohesion when a child had Batten disease, a progressive LTI, compared to families where the child had a less serious neurological condition (Labbe, 1996, as cited in Knafl & Gillis, 2002). Greater appreciation of life and one's interpersonal relationships may be a product of support shown by friends, family, and community members. Members of the community may be motivated to rally around a family when they know there is a good likelihood of survival. Evidence of this is seen in the number of support groups, fundraisers, and special events held for more common LTIs, such as cancer. The care of children with a non-cancer related LTI often extends over a greater duration of time when compared to curable conditions (Monterossa et al, 2007). Over time mothers may experience a decline in personal relationships as friends and extended family members become less available to help and their own caregiving demands increase. Mothers of children with progressive illness may also feel less supported by their medical team. Researchers in Western Australia found that parents actively caring for children with a LTI other than cancer reported that discussions about diagnosis and treatment were often fragmented and the severity of their child's illness was routinely de-emphasized (Monterosso et al.).

Congruency of couples' growth perceptions was tested by examining where each partners' PTGI scores fell in relation to one another. Results illustrate that there are no differences in the proportion of couples having both high or both low scores compared to couples where one partner has a high score and the other has a low score. While this lack of variation in the number of couples with congruent and incongruent scores implies that there is no relationship between the

scores of partners, further testing indicates that couples scores are positively correlated with one another. Simple linear regression shows that the Relating to Others scores of couple-dyads are significant predictors of one another, as is couples' growth in the area of Spiritual Change. Researchers that have examined growth in couples where one partner was diagnosed with an illness have found interpersonal relationships and couple dynamics to be related to personal growth (Manne et al., 2004; Ruvolo & Brennan, 1997; Thorton & Perez, 2006; Weiss, 2004). Consistent with the areas identified in the current study, positive reframing (Thorton & Perez) and a communication style characterized by the expression of feelings, mutual discussion of issues, and understandings the others point of view (Manne et al., 2006) have been associated with personal growth in the context of a couple's relationship. While, the current results are insufficient to make claims about how couples caring for a child with a LTI may influence one another's growth, this study serves as a valuable introduction to personal growth in these couples.

Limitations and Future Considerations

A limitation of the convenience method of sampling used in the Caregiving Parents Study is that parents who expressed an interest in participating may not be representative of all parents who have a child with a LTI. With respect to the current study, the couples who volunteered and returned completed surveys may not be representative of couples who are together caring for a child. The demand associated with caring for a child with a LTI may not allow for couples with the greatest caregiving burden to take part in research. Although investigators of the Caregiving Parent Study employed a variety of techniques to recruit parents, the couples that made-up the current sample is fairly uniform. Half of the parents have a university undergraduate or graduate degree and nearly half reported having an annual income of more than \$100 000. Seventy percent of the fathers and 47% of mothers reported currently or formerly working in a professional or management role.

Given that the current study is a secondary analysis of data collected to examine individual factors that influence positive outcomes in parent caregivers, the demographic survey

used did not ascertain information relevant to couples or relationship factors. For example, no measures were included to quantify the quality of a couple's relationship, such as marital satisfaction, family dynamics or cohesion, communication or problem solving style. The current study suggests that couples' interpersonal and spiritual growth scores are positively correlated, but the restricted data limits the ability to make assumptions about whether scores of mothers and fathers are dependent on one another or how partners may influence one another's growth. An undertaking of longitudinal research, perhaps using a mixed methods approach, seems more appropriate to address this question. Future research interested in examining personal growth in couples will be strengthened by the inclusion of measures that allow for in depth dyadic analysis of the associations between growth and relationships factors.

In addition to employing longitudinal research to examine how couples may influence each others' personal growth, this type of study design would also be valuable in exploring how age of parent, age of ill child, and time since diagnosis may affect growth. Perhaps, younger fathers and fathers with younger children experienced more growth due to greater levels of engagement with children and involvement in family matters not typical in previous generations. Future research would be strengthened by ascertaining detailed information about the duties and tasks that each parent is responsible for, as well as perceptions of burden and benefit they associated with their caregiving role.

Importance of religion was significantly related to personal growth in the current study. Although the Caregiving Parent Study used the Spiritual Involvement and Belief Scale (Hatch, Burg, Naberhaus, Hellmich, 1998) to collect information on spirituality, this measure was not included in this secondary analysis. Given terminology used in the demographic survey, the strong relationship between spirituality and personal growth that has been documented by past researchers (Cadell et al., 2003; Helgeson et al., 2006) may have been minimized. Nowhere on the demographic survey were parents asked about spirituality. The placement of the question "how important is religion to you?" followed an open-ended question about religious affiliation.

Because of wording and placement of this item, some parents may have interpreted this question as applying only to organized religion. One parent gave separate responses to show that she considers spirituality to be very important, whereas religion is not as important. Future researcher exploring moderators of personal growth should be cautious about wording questions in a manner that acknowledges the diversity of their participants. Specific to the issue of religion and spirituality, it is recommended that the wording of demographic surveys use both terms either in one question or under separate items.

Wording on the PTGI may have also led to an underestimate of growth in parents. Parents were asked to indicate the degree that “change occurred in your life as a result of your child’s illness”. As suggested by previous researchers who explored growth associated with bereavement, asking people to reflect on changes in relation to a specific event may narrow the timeline too closely to capture the full extent of positive outcomes related to caregiving (Cadell & Sullivan, 2006). In the current study, parents may have experienced growth due to factors external to their child’s illness, such as personal trauma or crisis. Given the genetic nature of some pediatric LTIs, it is probable that there are parents in the sample who had family members die of the same illnesses their children have been diagnosed with. One reason why younger parents may have reported greater growth may be that older parents no longer attribute the changes in their lives to their child’s illness, but to the acquisition of wisdom and insight that comes with age. Future researchers will need to decide whether they want to include an event or situation as a point of reference when administering the PTGI. The alternative would be to simply ask participants to indicate the degree that change has occurred. An advantage of using a mixed method study design in this situation would be that researchers could ascertain information directly from parents regarding the specific circumstances that might have led to positive outcomes.

Further exploration into how a child’s diagnosis may affect family dynamics and the well-being of family members, including parents, siblings, and the ill child, is strongly

recommended. Insights gained through such research may help minimize inaccurate assumptions and the broad generalizations that are often made regarding families and children with different types of illnesses and disabilities. Researchers are encouraged to examine the meaning that parents apply to a diagnostic label and how they may acquire their understanding of illness trajectory and prognosis. Do parents rely mainly on information shared by physicians or do they seek out information from other sources, such as the internet and other caregiving parent? For those interested in exploring the experiences of parents of children with LTIs, I would suggest that the category researchers and physicians associate with a given condition is less important than the meaning the family has assigned to the child's diagnosis. A limitation of the current study is that parents were not involved in assigning their child to a diagnostic category. It is recommended that future researchers investigating the experiences of parent caregivers acquire this information directly from parents.

In order to gain a more accurate representation of the severity of a child's illness, it would be beneficial to inquire about the types of activities and functional skills for which a child requires support and the level of support that is typically required. The current study did not look at respite care or the contribution made by paid caregivers, two areas that may influence perceptions of burden and growth. Personal growth of mothers in the current study is significantly related to community size. An extension of this finding would be to consider personal growth in relation to a family's proximity to care facilities and availability of resources, including formal and informal support services for family members.

Finally, although beyond the scope of the current project, future researchers may consider exploring the contrast between families caring for a child with a LTI in Canada and those in the United States. Stark differences were noted between where couples from the two countries are accessing care for their children. In addition, some of the American parents provided unsolicited qualitative comments about the stress and time demand associated with managing insurance claims and appeals. Contrasting the experiences of parent caregivers from

countries with either socialized or private health care systems would provide insight into how policies and the availability of resources may affect positive outcomes of families.

Implications for Social Work

Although a handful of studies have examined personal growth in couples where one partner is diagnosed with an illness, currently there is nothing in the literature on personal growth in couples caring for a child with a LTI. The present study serves to fill this void by examining how couples who are together actively caring for a child with a LTI experience personal growth. This investigation provides a more balanced and complete understanding of the parental experience, in contrast to traditional research in the field on pediatric illness and disability that has focused on challenges of caregiving and often neglected to include the voice of fathers. It has been proposed that positive outcomes associated with caregiving be explored in greater detail. This suggestion is relevant to three areas of interest in the practice of social work: the potential for individuals to undergo positive change following adversity, the role of spirituality and meaning making in the healing process, and strengths-based assessment and intervention practices.

Enhancing understanding of how couples experience growth along with the distress, grief, and guilt that accompanies a child's diagnosis is essential to a strengths-based approach to assessment and intervention strategies. Social workers play a valuable role in providing support to couples whose children are living with and dying from a LTI. Support can begin by helping parents deal with the shock and disbelief of their child's diagnosis, while emphasizing the importance of remaining physically and emotionally available to their child (Cincotta, 2004). The role of a social worker on a pediatric palliative care team often extends beyond supporting the patient to supporting family, friends, and members health care team (Cincotta). In their efforts to facilitate well-being, social workers need to be comfortable discussing issues with children and adults that may be considered taboo under different circumstances.

Social workers need to be available to discuss a range of issues and concerns with parents. Given what is known about factors affecting positive and negative outcomes of families, parents may benefit from having opportunities to reflect upon and consider the role of religion and spirituality in their lives. They may find comfort in sharing concerns regarding their relationship with their partner or children, friends or members of their extended family. Social workers and team members should be cognizant of how the current life-stage of a parent may influence the beliefs and attitudes he or she holds about caregiving duties, family responsibilities, or the illness and death of a child. Parents need to know that they will not be judged because of the challenges they admit to and the care of their child will not be compromised because of their opinions or actions.

Parents may also seek guidance from social workers for more concrete problems such as their own physical ailments or financial strain. The physical challenges associated with caregiving may be alleviated somewhat through the provision of respite care, in-home supports, and training in proper lifting and transferring techniques. The finding that difficulty managing costs associated with caregiving is related to personal growth, speaks to the importance of government funding and policies that provide grants and tax credits for families of children with LTIs. Numerous studies have documented the financial stress associated with caregiving (Corden et al., 2002; Monterosso et al. 2007; Morrod, 2004; Parker, 1996). Qualitative comments of parents in the current study identified added experiences associated with home renovations, transportation to medical appointments and specialized schools, and medication and equipment not covered by health insurance. A few parents shared that they make too much money to qualify for subsidies, yet not enough to avoid the strain associated with providing quality care for their child.

Members of the medical team should be respectful of the financial demands associated with caregiving. Supportive actions taken by health care professionals may include minimizing travel to and from hospital by coordinating medical appointments or, when appropriate, working

with doctors at a satellite program so families may receive certain treatments closer to home. Professionals should also strive to share information with parents about cost effective programs or interventions. Parents often discuss strategies used with nurses and physicians that they can then share with other parents in similar situations. Examples may include disseminating information about subsidized day camps or after school programs for children with special needs, or information about local hotels that give discounts to families who have a child in the hospital.

Social workers have a very important role in ensuring families are aware of all services and funding that are available to them. They should never make assumptions that a family would not be interested in accessing supports. Resources that may seem minor to an outsider may be invaluable to a parent struggling to meet the needs of his or her child. Social workers should also be available to provide guidance in completing application forms and assist in collecting the documentation required to prove a child's eligibility. These tasks can be daunting for a parent providing care to a child with a LTI.

In light of differences between mothers of children with curable and progressive illnesses in the areas of interpersonal growth and appreciation of life, health care providers should be cognizant of how various conditions may contribute to an individual's outlook. It should be emphasized that the meaning a professional attaches to a given diagnosis may not match the meaning a parent assigns to his or her child's condition. The need for communication that is clear and thorough cannot be overemphasized. While discussions about treatment protocols and symptom management are common in the day-to-day dialogues of medical staff, parents are being presented with information that is foreign to them. Information should be repeated and revisited in a respectful manner to ensure it is understood. Perhaps most importantly, members of the medical team should remember that what they say is equally important as what they hear. Active listening is key to good communication and instrumental in establishing and maintaining supportive relationships with the family members they serve.

The current research adds to the small number of studies that have ascertained information from mothers and fathers who are actively caring for children with a range of life-threatening medical conditions. Though the number of pediatric palliative care articles reporting the perspective of parents has increased substantially since 2003 (Macdonald et al., in press), there continues to be relatively few empirical studies focussing on parents who are active caregivers for a child with a LTI other than cancer. Studies striving to include the perspectives of these families often rely on retrospective reports from bereaved parents. Frequently researchers are concerned with parents' evaluations of the care they received from health professionals, rather than the experience of providing care for their dying children. Social workers employed in hospitals are in an ideal position to pursue research with families caring for children with various life-threatening conditions.

It is hoped that this research will not only serve to inform social workers and other professionals about the potential for positive outcomes, but it will help couples to better understand the experiences of one another and validate the range of personal challenges and triumphs that come with caring for a child with a LTI. Findings from the current investigation not only add to the personal growth literature, but are equally relevant to the fields of pediatric palliative care and parental functioning in the context of childhood illness.

Conclusion

The findings of this research show that significant differences do exist between the mean Total Growth scores of mothers and fathers, but there are no differences in subscale scores of the PTGI. Results also indicate that there are demographic factors that influence growth in specific areas. The greatest influence of these variables is noted in personal growth associated with interpersonal relationships, as illustrated by the number of significant findings between demographic factors and scores on the Relating to Others scale.

In most cases, the demographic variables serving to influence personal growth differ between fathers and mothers, but overlap was also seen. Growth scores of fathers are related to

age of parent, age of child, time since diagnosis, how well income meets needs, and importance of religion. The growth scores of mothers are related to community size, how well income meets needs, importance of religion, and diagnostic category of child's condition. The degree of difficulty managing costs associated with caregiving was the only variable related to growth scores in the full sample of parents, but not to the scores of mothers or fathers when assessed separately.

Assessing the degree of congruency of personal growth reported by couples illustrates that couple-dyads are no more likely to report similar degrees of growth than they are to report opposite degrees of growth. Furthermore, in cases where partners did have opposite degrees of growth, that is, one partner had a high score relative to his or her gender median and the other partner had a low score, it is just as likely that the wife will have the high score as it is the husband. Though these findings seem to imply that couples do not influence each others growth, additional test results indicate that in the areas of interpersonal growth and spiritual change the score of one partner is highly predictive of growth reported by his or her partner.

To effectively support couples caring for a child with a LTI, it is essential that social workers and members of the health care team strive to include both mothers and fathers. Members of pediatric palliative care teams are encouraged to challenge their own stereotypes and assumptions regarding gender roles. Similar to the idea of cultural competence, it is recommended that ideas about gender patterns serve as merely a starting point in informing clinical practice. Recognizing the importance of looking beyond gender to the individual will facilitate the creation of support strategies and intervention models that meet the needs of each family member.

APPENDIX A

Caregiving Parent Questionnaire Package

Study ID#: _____

Demographic Form

**Caregiving Parents of Children with Life-Limiting Illnesses:
Beyond Stress and Coping to Growth**
Principal Investigator: Dr. Susan Cadell

Present location of child:

Name of region or city: _____

Province/State: _____

- Home
- Hospital
- Hospice
- Other: Please specify: _____

Please indicate where your child accesses care (at least more than once per year):

- Home
- Hospital
- Hospice
- Other: Please specify: _____

Definition of caregiver:

What we mean by CAREGIVER in this study: a parent or guardian who provides care for a child who has a life-limiting illness and is not paid to do so.

What we mean by CARE: anything you do for your child because he or she has a life-limiting illness. Some examples are:

- Household chores that now take more time (for example, extra laundry or preparing special foods)
- Direct care for the child (bathing, feeding, skin care, giving medications, wound care, toileting, transferring between bed and chair)
- Additional time you spend with the child, including keeping him or her company and being present for safety reasons
- Arranging appointments, arranging for help from paid or unpaid others
- Attending health care appointments
- Transportation
- Time spent in the hospital

Please note that this is a partial list.

1a. You are caring for your ...

- Daughter
- Son
- Other (please specify): _____

1b. Are you caring for more than one child with a life-limiting illness?

- Yes
- No

1c. Do you presently live with your child?

- Yes
- No

**1d. Has there been a change in your living arrangements because of your child's illness?
Check all that apply.**

- No change
- I moved to another town/city
- Other (please specify): _____

**1e. Has there been a change in your child's living arrangements because of his/her illness?
Check all that apply.**

- No change
- My child moved in with me
- My child moved to a another town/city
- Other (please specify): _____

2a. Size of community – Caregiver

- Metropolitan area (1 million +)
- Large city (100,000 – 999,999)
- Medium city (30,000 – 99,999)
- Small city (10,000 – 29,999)
- Town (1,000 – 9,999)
- Village (300 – 999)
- Hamlet (299 or fewer)
- Other (please specify): _____

2b. Size of community – Child

- Metropolitan area (1 million +)
- Large city (100,000 – 999,999)
- Medium city (30,000 – 99,999)
- Small city (10,000 – 29,999)
- Town (1,000 – 9,999)
- Village (300 – 999)
- Hamlet (299 or fewer)
- Other (please specify): _____

Study ID#: _____

3. Your marital status:

- | | |
|---|--|
| <input type="checkbox"/> Married or living as married | <input type="checkbox"/> Divorced or separated and not presently remarried |
| <input type="checkbox"/> Widowed | <input type="checkbox"/> Other (please specify): _____ |
| <input type="checkbox"/> Never married | |

4a. Your date of birth:

4b. Your child's date of birth:

5. Your gender:

- Female
- Male

6a. Your religious affiliation:

6b. Your child's religious affiliation:

6c. How important is religion to you?

- Very important
- Of medium importance
- Of little importance
- Not at all important

6d. How important is religion to your child? (If applicable)

- Very important
- Of medium importance
- Of little importance
- Not at all important

7. Highest level of education you have completed:

- Elementary school or less
- Some high school
- High school diploma
- Some college (including CEGEP) or trade school
- Diploma from college (including DEC) or trade school
- Attended university
- University degree
- Post-graduate degree
- Other (please specify): _____

Study ID#: _____

8. Ethnic background (Caregiver)

Where were you born? _____

Province or State: _____

Country: _____

If you were not born in Canada (or the U.S), in what year did you come to Canada (or the U.S)? _____

To which ethnic or cultural groups did you or the majority of your ancestors belong on first coming to Canada (or the U.S)? *List more than one if necessary.*

Do you sometimes require someone to translate for you?

- Yes No

9. Your occupation (current or former)

- Clerical
- Laborer
- Management
- Professional
- Homemaker
- None
- Other (please specify): _____

10a. Your current employment status:

- | | |
|--|--|
| <input type="checkbox"/> Full-time | <input type="checkbox"/> Retired |
| <input type="checkbox"/> Part-time | <input type="checkbox"/> Not employed |
| <input type="checkbox"/> Paid leave | <input type="checkbox"/> Other (please specify): _____ |
| <input type="checkbox"/> Unpaid leave | |
| <input type="checkbox"/> Self-employed | |

10b. Does your current employment status allow you to take time to provide care?

- Yes, completely
- Only partially
- No

11. Has your employment status changed as a result of your caregiving role?

- Yes No

If yes, what was your previous employment status?

- | | |
|--|--|
| <input type="checkbox"/> Full-time | <input type="checkbox"/> Retired |
| <input type="checkbox"/> Part-time | <input type="checkbox"/> Not employed |
| <input type="checkbox"/> Paid leave | <input type="checkbox"/> Other (please specify): _____ |
| <input type="checkbox"/> Unpaid leave | |
| <input type="checkbox"/> Self-employed | |

12a. What is your average household income (before taxes)?

- | | |
|---|---|
| <input type="checkbox"/> Below \$19,999/year | <input type="checkbox"/> \$70,000 - \$79,999/year |
| <input type="checkbox"/> \$20,000 - \$29,999/year | <input type="checkbox"/> \$80,000 - \$99,999/year |
| <input type="checkbox"/> \$30,000 - \$39,999/year | <input type="checkbox"/> \$100,000 - \$119,999/year |
| <input type="checkbox"/> \$40,000 - \$49,999/year | <input type="checkbox"/> \$120,000 - \$139,999/year |
| <input type="checkbox"/> \$50,000 - \$59,999/year | <input type="checkbox"/> \$140,000 - \$199,999/year |
| <input type="checkbox"/> \$60,000 - \$69,999/year | <input type="checkbox"/> \$200,000 or more/year |

12b. How many people depend on this income?

_____ Adults (18+) _____ Child(ren)

12c. How well does your current income meet your needs?

- Completely
 Very well
 Adequately
 With some difficulty
 Not very well
 Totally inadequate

12d. Has your family income changed as a result of your child's illness?

- Yes No

If yes, in what way? _____

12e. Are you responsible for some costs resulting from the illness?

- Yes No

12f. If yes, generally, how difficult is it to manage the costs associated with caregiving and your child's illness?

Not at all difficult											Very difficult
1	2	3	4	5	6	7	8	9	10		

Comments: _____

13a. What is your child's diagnosis?

13b. When was he/she diagnosed? (month/year) _____

13c. How long have you been a caregiver for your child with a life-limiting illness? (months/years) _____

14. In the past month, how many hours per week have you spent caregiving? (As defined on Page 1)

_____ hours

15. Are there other family members, friends, or neighbours involved in unpaid caregiving?

No

Yes If yes, how many other unpaid caregivers are there and what is their relationship? _____

About how many hours of unpaid caregiving per week in total do these caregivers provide? _____

Additional Questions

- 1. If you have had to change your living arrangements or move since you started to be a caregiver for your child, please describe all changes in order.**

- 2. If possible, please describe where your child has lived since you began providing care, including any overnight stays in the hospital.**

Meaning in Caregiving

As stated on page one of the demographic form, what we mean by caregiver in this study is a parent or guardian who provides care for a child who has a life-limiting illness and is not paid to do so. Please rate how much you agree or disagree with the following statements.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. I feel it has been important to my child that I have been involved in caregiving.	1	2	3	4	5
2. Since becoming a caregiver, I feel differently about what things in life are worth the extra effort.	1	2	3	4	5
3. I've learned a lot about myself as a result of caring for my child.	1	2	3	4	5
4. My caregiving experience has changed my idea of what is important in a relationship.	1	2	3	4	5
5. My caregiving experience has led me to think of myself as more skillful and able.	1	2	3	4	5
6. Since becoming a caregiver, I don't worry as much about the little things in my life.	1	2	3	4	5
7. After going through some of the stresses of caregiving, I feel that can handle just about anything.	1	2	3	4	5
8. I take satisfaction in doing things the way I know she/he has always liked.	1	2	3	4	5
9. My religion or spiritual beliefs have helped me handle this whole experience.	1	2	3	4	5
10. I feel that I have become a stronger person since becoming a caregiver.	1	2	3	4	5
11. I feel less afraid now of other things that might come along in the future.	1	2	3	4	5
12. I am better able to accept my role as caregiver because I feel that my child needs me.	1	2	3	4	5

Rosenberg Self-Esteem Scale

Below is a list of statements dealing with your general feelings about yourself. Please rate how much you agree or disagree with the following statements by putting a check mark in the appropriate box.

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
1. On the whole, I am satisfied with myself.					
2. At times, I think I am no good at all.					
3. I feel that I have a number of good qualities					
4. I am able to do things as well as most other people.					
5. I feel I do not have much to be proud of.					
6. I certainly feel useless at times.					
7. I feel that I am a person of worth, at least on an equal plane with others.					
8. I wish I could have more respect for myself					
9. All in all, I am inclined to feel that I am a failure.					
10. I take a positive attitude toward myself					

LOT-R

Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements. There are no “correct” or “incorrect” answers. Answer according to your own feelings, rather than how you think “most people” would answer.

	I Agree A Lot	I Agree A Little	I Neither Agree Nor Disagree	I Disagree A Little	I Disagree A Lot
1. In uncertain times, I usually expect the best.	1	2	3	4	5
2. It's easy for me to relax.	1	2	3	4	5
3. If something can go wrong for me, it will.	1	2	3	4	5
4. I'm always optimistic about my future.	1	2	3	4	5
5. I enjoy my friends a lot.	1	2	3	4	5
6. It's important for me to keep busy.	1	2	3	4	5
7. I hardly ever expect things to go my way.	1	2	3	4	5
8. I don't get upset too easily	1	2	3	4	5
9. I rarely count on good things happening to me.	1	2	3	4	5
10. Overall, I expect more good things to happen to me than bad.	1	2	3	4	5

SIBS

How strongly do you agree with the following statements? Please circle your response.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1. I set aside time for meditation and/or self-reflection	5	4	3	2	1
2. I can find meaning in times of hardship.	5	4	3	2	1
3. A person can be fulfilled without pursuing an active spiritual life.	5	4	3	2	1
4. I find serenity by accepting things as they are.	5	4	3	2	1
5. I have a relationship with someone I can turn to for spiritual guidance.	5	4	3	2	1
6. Prayers do not really change what happens.	5	4	3	2	1
7. In times of despair, I can find little reason to hope.	5	4	3	2	1
8. I have a personal relationship with a power greater than myself.	5	4	3	2	1
9. I have had a spiritual experience that greatly changed my life.	5	4	3	2	1
10. When I help others, I expect nothing in return.	5	4	3	2	1
11. I don't take time to appreciate nature.	5	4	3	2	1
12. I have joy in my life because of my spirituality.	5	4	3	2	1
13. My relationship with a higher power helps me love others more completely.	5	4	3	2	1
14. Spiritual writings enrich my life.	5	4	3	2	1

Study ID#: _____

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
15. I have experienced healing after prayer.	5	4	3	2	1
16. My spiritual understanding continues to grow.	5	4	3	2	1
17. I focus on what needs to be changed in me, not on what needs to be changed in others.	5	4	3	2	1
18. In difficult times, I am still grateful.	5	4	3	2	1
19. I have been through a time of great suffering that led to spiritual growth.	5	4	3	2	1
20. I solve my problems without using spiritual resources.	5	4	3	2	1
21. I examine my actions to see if they reflect my values.	5	4	3	2	1
22. How spiritual a person do you consider yourself? (with '5' being the most spiritual)	5	4	3	2	1

CES-D

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

During the past week...

	Not at all	Rarely	Some or a little of the time	A moderate amount of the time	Most or all of the time
1. I was bothered by things that usually don't bother me.					
2. I did not feel like eating; my appetite was poor.					
3. I felt that I could not shake off the blues even with help from my family or friends.					
4. I felt I was just as good as other people.					
5. I had trouble keeping my mind on what I was doing.					
6. I felt depressed.					
7. I felt that everything I did was an effort.					
8. I felt hopeful about the future.					
9. I thought my life had been a failure.					
10. I felt fearful.					
11. My sleep was restless.					
12. I was happy.					
13. I talked less than usual.					
14. I felt lonely.					

Study ID#: _____

During the past week...	Not at all	Rarely	Some or a little of the time	A moderate amount of the time	Most or all of the time
15. People were unfriendly.					
16. I enjoyed life.					
17. I had crying spells.					
18. I felt sad.					
19. I felt that people dislike me.					
20. I could not get "going".					

Burden Scale

Please rate how much the following statements describe yourself:

	Not at all	Somewhat	Neutral	Quite a bit	Completely
1. You are exhausted when you go to bed at night.	1	2	3	4	5
2. You have more things to do than you can handle.	1	2	3	4	5
3. You don't have time just for yourself.	1	2	3	4	5
4. You work hard as a caregiver but never seem to make progress.	1	2	3	4	5

PTGI

Indicate for each of the statements below the degree to which this change occurred in your life as a result of the illness of your child, using the following scale.

0 = I did not experience this change.

1 = I experienced this change to a very small degree.

2 = I experienced this change to a small degree.

3 = I experienced this change to a moderate degree.

4 = I experienced this change to a great degree.

5 = I experienced this change to a very great degree.

- _____ 1. I changed my priorities about what is important in life.
- _____ 2. I'm more likely to try to change things which need changing.
- _____ 3. I have a greater appreciation for the value of my own life.
- _____ 4. I have a greater feeling of self-reliance.
- _____ 5. I have a better understanding of spiritual matters.
- _____ 6. I more clearly see that I can count on people in times of trouble.
- _____ 7. I have a greater sense of closeness with others.
- _____ 8. I know better that I can handle difficulties.
- _____ 9. I have a greater willingness to express my emotions.
- _____ 10. I am better able to accept the way things work out.
- _____ 11. I can better appreciate each day.
- _____ 12. I have greater compassion for others.
- _____ 13. I'm able to do better things with *my* life.
- _____ 14. New opportunities are available which wouldn't have been otherwise.
- _____ 15. I put more effort into my relationships.
- _____ 16. I have a stronger religious faith.
- _____ 17. I discovered that I'm stronger than I thought I was.
- _____ 18. I learned a great deal about how wonderful people are.
- _____ 19. I developed new interests.
- _____ 20. I better accept needing others.
- _____ 21. I established a new path for my life.

Appendix B

Posttraumatic Growth Inventory Items by Scale

Relating to Others

I more clearly see that I can count on people in times of trouble.

I have a greater sense of closeness with others.

I have greater compassion for others.

I put more effort into my relationships.

I better accept needing others.

I learned a great deal about how wonderful people are

I have a greater willingness to express my emotions.

New Possibilities

I'm more likely to try to change things which need changing.

I'm able to do better things with my life.

New opportunities are available which wouldn't have been otherwise.

I established a new path for my life.

I developed new interests.

Personal Strength

I have a greater feeling of self-reliance.

I know better that I can handle difficulties.

I discovered that I'm stronger than I thought I was.

I am better able to accept the way things work out.

Spiritual Change

I have a better understanding of spiritual matters.

I have a stronger religious faith.

Appreciation of Life

I have a greater appreciation for the value of my own life.

I can better appreciate each day.

I changed my priorities about what is important in life.

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