Virginia Commonwealth University

VCU Scholars Compass

Theses and Dissertations

Graduate School

2008

Exploring the Experience of Benefit Finding in Parents of Children with Cancer: A Grounded Theory Study

Carol E. Zogran
Virginia Commonwealth University

www.manaraa.com

Exploring the Experience of Benefit Finding in Parents of Children with Cancer:
A Grounded Theory Study

A dissertation submitted in partial fulfillment of the requirements for the degree of

Doctor of Philosophy at Virginia Commonwealth University.

By

Carol E. Zogran

B.S.N. The Catholic University of America, 1978

M.S.N. Lehman College of the City University of New York, 1981

Director: Rita H. Pickler, Ph.D., R.N.
Professor and Chair
Department of Family and Community Health Nursing

Virginia Commonwealth University
Richmond, Virginia
April 2008

Acknowledgement

I am fortunate to have chosen as the chair of my committee Dr. Rita Pickler, whose guidance, feedback, and support provided me with the inspiration and encouragement to get through every step of this study. Her expertise in grounded theory has been invaluable. Additionally, I thank the members of my committee, Dr. Gayle Roux, Dr. Debra Lyon, and Dr. Gita Massey, for their patience and expertise and for the care each of them took in reviewing each phase of the study.

I would also like to express my appreciation for other faculty in the School of Nursing who influenced my thinking and ability to conceptualize this study: Dr. Janet Younger, Dr. Nancy McCain, Dr. Inez Tuck, and Dr. Patty Gray.

Thank you to all my classmates for support and encouragement. You helped me maintain my sanity.

Thank you to my parents, Ray and Jody Zogran, without whose support this would have been impossible. You've been my greatest cheerleaders.

Thank you, Walter, Sam, Tesia, and James, for all that you have put up with for all these years. Your love and admiration grounds me. Thank you, Loey, for all that you do.

To my angel, Jarryd. Your spiritual company has guided me and held me up throughout this endeavor.

ii

And most of all, thank you to the parents who shared their stories with me. I am filled with awe and inspiration thinking about your strength, and I am indebted to you for sharing the journey with me.

From "The Invocation to Kali"

Help us to be the always hopeful
Gardeners of the spirit
Who know that without darkness
Nothing comes to birth
And without light
Nothing flowers.
– by May Sarton

Table of Contents

List of Tables

List of Figures

Abstract

EXPLORING THE EXPERIENCE OF BENEFIT FINDING IN PARENTS OF
CHILDREN WITH CANCER: A GROUNDED THEORY STUDY

By Carol E. Zogran, Ph.D., R.N.

A dissertation submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy at Virginia Commonwealth University.

Virginia Commonwealth University, 2008

Director: Rita H. Pickler, Ph.D., R.N., Professor and Chair, Department of Family and
Community Health Nursing

The diagnosis of cancer in a child is one of the most significant stressors a parent
can experience, and research in the area of stress-related effects of illness on parents has
emerged in many areas. The majority of studies have focused on the potential or actual
negative impact on parents during and after treatment of their child's illness. However,
studies that initially set out to explore the difficulties associated with coping with
childhood cancer found that parents often reported positive aspects about the experience.
There is now increasing interest and support for the study of "positive-health" factors that
contribute to protective variables influencing the health and well being of parents, such as
benefit finding. The present study aimed to illuminate the process of benefit finding in

parents of children with cancer and to develop a theoretical model of this process based on the findings.

This grounded theory study resulted in a conceptual model that organized and depicted the constructs and structures related to the process of benefit finding. Through constant comparative analysis, the Basic Psychosocial Problem was identified as being overwhelmed with fear. The parents identified intervening conditions that helped move them from feeling overwhelmed to feeling that they could manage the fear. Many parents identified a specific event, an "epiphenomenon" that created a turning point for them. This event, along with the intervening conditions, moved the parent from being overwhelmed to managing/transforming the fear, which was the Basic Psychosocial Process. The strategies that the parents identified as helping to manage the fear are being in the present, being strong, having faith/maintaining hope, and making meaning out of the event, of which benefit finding was the major component. This entire process occurred within the context of being a parent, as this awareness colored the entire experience. Benefit finding emerged as both a strategy and an outcome within this process and encompassed a growth in character, strengthening of relationships, and a gain in perspective. The theoretical model and substantive theory that emerged during the course of this study provide a way to understand this process in parents of children with cancer.

CHAPTER 1

INTRODUCTION

Over the past four decades, extensive research has been published on the
psychological impact of childhood cancer on parents (Hinds, Birenbaum, & Clarke-
Steffen, 1996; Iles, 1979; Kazak & Meadows, 1989; Koocher & O'Malley, 1981; Kupst,
1984; Kupst & Schulman, 1981; Lansky, Cairns, Hassanein, Wehr, & Lowman, 1978;
Woodgate, 2003), perhaps because the experience is viewed as one of the most traumatic
events for a parent, evoking empathic responses across a broad range of disciplines.
According to the *Diagnostic and Statistical Manual of Mental Disorders–IV* (American
Psychiatric Association, 1994, p. 424), learning that one's child has cancer, or another
life-threatening disease, is considered stressful enough to be a qualifying event for
posttraumatic stress disorder. The focus of research in the area of coping with the
diagnosis of childhood cancer has shifted over the past 40 years, as the cure rate of this
devastating disease has grown exponentially. In the 1950s and 1960s, less than a 10
percent survival rate existed for acute lymphoblastic leukemia, the most common form of
pediatric cancer (Kupst, 1994). The current 5-year cancer-free survival rate for children
with cancer is 79%, and the 10-year rate is approaching 75% (Rowland et al., 2004).
Earlier studies focused on dealing with the nearly inevitable death of the child, mostly

1

from the perspective of the parents. As treatment and cure rates have improved,

researchers have focused more on cancer as a chronic health condition and how coping

strategies have changed, utilizing both qualitative and quantitative studies from a variety

of theoretical perspectives (Kupst, 1994).

Statement of the Problem

A diagnosis of cancer in a child is undoubtedly one of the most significant

stressors a parent can experience, and research in the area of stress and stress-related

effects of illness on parents has emerged in many areas of psycho-oncology. Most studies

have focused on the potential or actual negative impact on parents during and after

treatment of their child's illness. However, many studies that initially set out to explore

the difficulties associated with coping with childhood cancer found that parents often

report positive aspects about the experience (Barbarin, Hughes, & Chesler, 1985; Best,

Streisand, & Cantania, 2001; Sloper, 2000). Thus, researchers have developed an

increasing interest in and support for the study of "positive-health" factors such as

positive coping, resilience, and finding purpose and meaning, which contribute to

protective variables that influence the health and well-being of the parents. The

Committee on Future Directions for Behavioral Health and Social Science Research at

the National Institutes of Health has called for increased research into understanding and

promoting optimal human functioning (Singer & Ryff, 2001).

One variable that may influence successful coping and support optimal human

functioning is the concept of benefit finding. Benefit finding refers to one's ability to

identify benefits or perceive profit as a result of the presence of a specific stressor in

one's life (Tennen & Affleck, 2002). Benefit finding is one of many positive characteristics of psychological functioning that is studied within the realm of positive psychology. Positive psychology refers to the scientific study of optimum human functioning. It involves identifying and understanding human strengths and how the interactions of these give rise to good adaptation, growth, and well-being (Pearsall, 2003; Snyder & Lopez, 2002). Positive psychology emerged as a "movement" in the late 1990s, having started in the mid-1970s as the field of psychology shifted its focus from identification of pathology and subsequent treatment of disorders toward prevention and, later, health promotion.

However, for hundreds of years, philosophers, theologians, artists, and writers have presented the human experience of suffering and the possibility for growth that emerges as a result. Perhaps it was the republication of Frankl's (1985) *Man's Search for Meaning* that helped spark the interest of researchers in various disciplines to study the experience scientifically. Positive changes following a crisis or trauma have been reported empirically related to chronic illness, heart attacks, cancer, bone marrow transplants, HIV and AIDS, military combat, natural disasters, plane crashes, bereavement, injury, in parents of children with disabilities, rape, sexual assault, and other violent crimes (Abraido-Lanza, Guier, & Colón, 1998; Affleck & Tennen, 1996; Affleck, Tennen, Croog, & Levine, 1987; Best et al., 2001; Cordova, Cunningham, & Carlson, 2001; Davis, Nolen-Hoeksema, & Larson, 1998; Evers, Kraaimaat, & van Lankveld, 2001; Fontana & Rosenheck, 1998; Frazier, Conlon, & Glaser, 2001; Janoff-Bulman, 1992; McMillen, Smith, & Fisher, 1997; Pargament, 1997; Park, Cohen, &

Murch, 1996; Polatinsky & Esprey, 2000; Schnurr, Rosenberg, & Friedman, 1993; Tedeschi & Calhoun, 1996; Tennen, Affleck, Urrows, Higgins, & Mendola, 1992; Weiss, 2002).

In addition to benefit finding, positive changes have been labeled resilience, posttraumatic growth, transformational growth, thriving, and flourishing. In the field of nursing, constructs such as mastery and health-within-illness are other examples of positive characteristics that have been studied empirically. Psycho-oncology research has largely ignored illuminating the process by which benefit finding, as related to the impact of the cancer experience on the family, is an important endeavor. It is hoped that greater understanding of the process of benefit finding in parents of children with cancer will provide a foundation for the development of new interventions to support benefit finding and to promote growth and well-being.

<div align="center">Significance and Background of the Study</div>

Improved survival of pediatric cancer patients is one of the great medical success stories of the 20th century, with 5-year survival rates increasing from less than 50% to 80% over the past 30 years (American Cancer Society, 2007). However, despite this tremendous progress, cancer remains the leading cause of disease-related death among children and adolescents, with an estimated 10,730 diagnosed cancer cases and 1,490 cancer-related deaths expected to occur in 2008 among children aged 0 to 14 years (American Cancer Society, 2007).

The National Institute of Nursing Research, with support from the Office of Rare Diseases—both of the National Institutes of Health—convened the working group

"Moving the Research Agenda Forward for Children with Cancer" in August 2003. The group consisted of the leading experts in childhood cancer, who met to develop a research agenda for pediatric oncology for the 21st century. Among the topics discussed, quality of life and family responses to childhood cancer emerged as research priorities, largely due to the increased understanding of the importance of focusing care on each family member and the expanded view that recognizes the importance of quality of life in treatment outcomes.

The ability of parents to cope with and adapt to the multiple stressors associated with the diagnosis and treatment of cancer in their child is likely to affect the child's quality of life. From a family-systems perspective, what happens to one family member (the child) affects the others, and, reciprocally, how the family responds influences the child's functioning. It is a circular process whereby continuous adjustment and adaptation occur. Although this process has been recognized, research has generally focused on the negative aspect of the cycle (i.e., parental anxiety and its effect on the child). However, research has shown that systemic reverberations may be positive and adaptive, as well. Effective parental coping, for example, was found to protect children from feeling hopeless during their treatment for cancer (Blotcky, Raczynski, Gurnitch, & Smith, 1985).

Research related to the impact of the cancer experience on the family and how the parents' response influences the quality of life of the child is being published with greater frequency (Kazak, 2004), with the preponderance of the literature focused on the negative effects of this experience. The majority of studies approach the experience from a

pathology-oriented perspective in which symptoms and problems such as depression, anxiety, posttraumatic symptoms, and family dysfunction are measured and compared to the general population (Kupst, 1994). Increased research emphasis is needed on positive health concepts to understand how parents of children with cancer adjust positively to, and find benefit with, the cancer experience in order to develop appropriate interventions that support a positive approach.

<center>Study Purpose</center>

The purposes of this study were to develop an understanding of the process of benefit finding in parents of children with cancer and to develop a theoretical model of parental benefit finding within the experience of having a child with cancer.

<center>Research Question</center>

The study was guided by the following research question: "What is the process by which parents of children with cancer come to find benefit within this experience?"

<center>Methodology</center>

Given the conceptual ambiguity of the concept of benefit finding and my desire to understand not only how families experience it but also the process used by families to "get to" this experience, I selected a grounded theory approach to best address the research question. The grounded theory approach is used to explore social processes that occur within human interactions in a given context. Using the specific procedures outlined in grounded theory (Glaser, 1978, 1998; Glaser & Strauss, 1967), explanations of key social processes or structures are developed, having been derived from or grounded in empirical data. The theory that emerges from this analysis can provide a new

understanding of the phenomenon that is generated from the data and can then be used as a basis from which to develop relevant interventions (Hutchinson, 1993).

Grounded theory is based on the conceptual framework of symbolic interactionism. An overview of the philosophy of symbolic interactionism is presented below, followed by a review of grounded theory.

Symbolic Interactionism

Although the symbolic interactionist perspective is primarily associated with George Mead, Herbert Blumer (1969) took Mead's ideas and developed them into a more systematic sociological approach. Blumer (1969) coined the term "symbolic interactionism":

> The term "symbolic interaction" refers, of course, to the peculiar and distinctive character of interaction as it takes place between human beings. The peculiarity consists in the fact that human beings interpret or "define" each other's actions instead of merely reacting to each other's actions. Their "response" is not made directly to the actions of one another but instead is based on the meaning which they attach to such actions. Thus, human interaction is mediated by the use of symbols, by interpretation, or by ascertaining the meaning of one another's actions. This mediation is equivalent to inserting a process of interpretation between stimulus and response in the case of human behavior. (p. 180)

According to Blumer (1969), three basic assumptions are associated with symbolic interactionism. The first one is that people, individually and collectively, act on the basis of the meanings that things have for them. That is, people first attach meaning to things and situations, then respond or act according to that meaning. This presupposes that the world exists separate and apart from the individual and that, through the process of interaction, the world is interpreted through the use of symbols (language).

The second assumption is that it is through the process of interaction among individuals that meaning emerges (Blumer, 1969). That is to say, the meaning an individual gives an interaction arises out of the ways in which others act to define things; they have agreed on the meanings attached to things in their environment.

Third, the interpretive process is never static; meanings are modified, redefined, relocated, and realigned as people interact (Blumer, 1969). Individuals actively shape their own future as they encounter new stimuli and form new meanings and new ways to respond through the interpretive process.

An important tenet of symbolic interactionism is "the idea that the individual and the context in which that individual exists are inseparable. Truth is tentative and never absolute because meaning changes depending on the context for the individual" (Benzies, 2001, p. 544). Thus, research conducted from the symbolic interactionism perspective entails exploring the process by which individuals interpret situations and their behavioral response based on the derived meaning.

Grounded Theory

Grounded theory emerged from the discipline of sociology as a technique used to derive theory from the experience of the participants. "Grounded" refers to the source of the data, which comes directly from the participants—from the ground up. It was developed by Glaser and Strauss (1967) and was based on symbolic interactionism. Grounded theory has been used most frequently to explore areas in which little previous research has been conducted or to gain alternative viewpoints in familiar areas of research. Because the interaction among participants is the main focus of observation,

grounded theory is an appropriate perspective from which to explore the experience of individual family members as well as the interrelatedness of their experiences.

Grounded theory is a form of field research, referring to studies that explore and describe phenomena in naturalistic settings (Streubert & Carpenter, 1999). Investigators conduct in-depth explorations of the practices, behaviors, beliefs, and attitudes of participants as they respond to a particular problem or concern, and, then, investigators develop a theoretically complete explanation or grounded theory that serves to elucidate the process (Glaser & Strauss, 1967). Grounded theory is theory that is derived directly from the data that have been systematically gathered and analyzed throughout the research process. In this way, the collection of data, analysis (through constant comparison), and eventual theory are closely related. The researcher begins with a substantive area of study and begins to generate conceptual categories as they emerge from the data. These data are then used as evidence to illustrate the concepts. As concepts are clarified and relationships among conceptual categories are identified, theory is formed (Glaser & Strauss, 1967).

The researcher must begin with an open mind to avoid having preconceived ideas about ways of classifying and correlating the data. One may have some general ideas or a theoretical perspective about the phenomenon of interest, but these must be held in abeyance to allow for the emergence of themes and theories from the data. Although "benefit finding" has been defined in previous studies, the intent of the present investigation was to explore how benefit finding is actually experienced and defined by

parents of children with cancer, examining both similarities and differences with the current literature.

Definitions

For the purpose of the present study, the following definitions were employed:

- *Parents*: Parents include the biological, step-, or adoptive parent with whom the child lives.

- *Child with cancer*: A child between 1 and 17 years of age who is currently in the maintenance phase of treatment for a diagnosed malignancy (leukemia, tumors, etc.).

- *Benefit finding*: Benefit finding is broadly conceived as the ability to identify and express benefits that arise from a negative life event.

Summary

This chapter presents an overview of the background and significance for the present study. The purpose of the study was to develop a substantive theory of the experience of benefit finding in parents of children with cancer through the use of grounded theory method. The following chapter reviews the literature that is relevant to the current study, focusing on what is known about benefit finding and related constructs as well as illuminating what is not yet understood about this concept.

CHAPTER 2

LITERATURE REVIEW

In order to cope with and adapt to the stressors associated with a diagnosis of cancer in their child, parents must find ways to reestablish equilibrium within their family. After a child is in remission, the shock and denial have generally subsided, and the psychosocial tasks for the parents change from a focus on their child's survival to include developing a philosophy of life that encourages the child to remain active and independent and fostering the growth and well-being of every family member. Models of growth and well-being have been developed or adapted from theories of coping and adjustment to include the potential for positive outcomes following trauma and adversity (e.g., Folkman, 1997; Janoff-Bulman, McPherson, & Frantz, 1997; O'Leary & Ickovics, 1995; Park & Folkman, 1997; Taylor, 1983; Tedeschi & Calhoun, 1995; Younger, 1991). These theories are all similar in that they propose that individuals have the potential to grow as a result of their experience with a traumatic or stressful event. Growth following adversity has been labeled thriving, posttraumatic growth, transformational or psychospiritual growth, and mastery of stress. All of these constructs grew out of the literature of stress and coping; each construct shares the conceptualization of personal growth occurring as a result of an individual engaging in the processes of coping and

11

meaning making following a stressful experience. Benefit finding is considered to be part of the meaning-making process in that an individual must engage in both making sense of and finding benefit within a stressful experience in order to derive meaning from the experience. This theoretical framework is depicted in Figure 1.

CRISIS/TRAUMA ⟶ Coping and Meaning Making ⟶ GROWTH

Making Sense + Benefit Finding
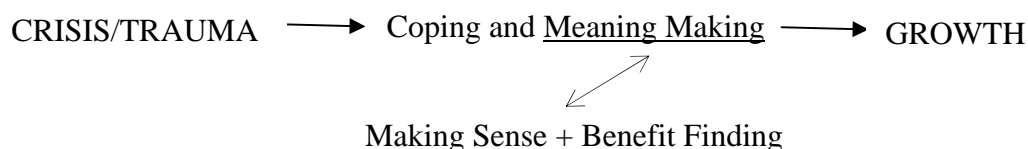
Figure 1. Theoretical Framework for Growth in a Stressful Experience

In qualitative research, the literature that is reviewed is considered a source of data and is initially useful in identifying the scope, range, intent, and type of related research that has been conducted in the area of interest (Chenitz & Swanson, 1986). It may be used throughout the research process as additional data are obtained to help clarify specific points of interest and provide insights related to the emerging data that may help guide the research process. Previous research is explored and examined for its reliability and applicability as it is compared to the analytic concepts and relationships among concepts that emerge in the developing theory. In this vein, the current review of literature begins with a focus on the research related to coping as the underlying framework for positive adaptation. Benefit finding and the related concepts of thriving, mastery of stress, and posttraumatic growth follow, focusing mainly on what is known about benefit finding in particular and why further research is needed on this concept.

A brief overview of coping in general is discussed prior to presenting a review of the literature on parental coping, which is explored within the field of psycho-oncology. The majority of studies in psycho-oncology related to childhood cancer have focused on how the child and parents cope with this crisis in an attempt to discover interventions to mitigate negative sequelae. How people cope with adversity is multifaceted; the study of coping with adversity should take into account the possibility of positive as well as negative responses if it is to be comprehensive. The literature on parental coping provides a context within which to place the concept of benefit finding as it has generally been conceptualized as an aspect of coping that contributes to positive adaptation.

<div align="center">General Overview of Coping</div>

The literature on coping and adaptation can be viewed as coming out of the field of psychoanalysis, where defense mechanisms were first identified as a way in which individuals deal with anxiety (Aldwin & Yancura, 2004). Defense mechanisms are construed as negative or maladaptive for the most part and are unconsciously employed to lessen psychic or emotional discomfort. People tend to use a particular defensive style in most circumstances, and the early study of these styles led to the initial understandings of how individuals cope with stress and trauma.

Coping styles are seen as adaptive processes to stress, which are responsive to situational demands. The focus on styles of coping was related to how people processed information about a particular stressor, dividing responders into those who suppress information or those who seek or augment information. This dichotomy continues to appear in the coping literature, taking on different names such as approach-avoidance and

emotion- versus problem-focused coping. A gradual shift in the field of coping research moved from viewing coping as a reflection of personality style to viewing coping as a process or series of processes that are flexible and responsive to situational demands.

Since the 1970s, research about how people deal with and adapt to stress has grown tremendously, with a variety of theoretical frameworks guiding the various studies. For the purpose of organization in the literature review presented here, studies related to parental coping with childhood cancer are divided into three general orientations: studies in which coping is viewed as a process with strategies of adaptation, studies that examine correlates of coping, and studies where coping as adaptation is the outcome.

Coping as Process/Adaptation

It is important to note that a distinction is made between coping strategies employed in everyday stressors and the strategies used to cope with traumatic experiences. Given that the experience of having a child diagnosed with cancer is significant enough to qualify as a trauma event in the *Diagnostic and Statistical Manual of Mental Disorders–IV* (American Psychiatric Association, 1994, p. 424), the studies reviewed here are all within the latter category. Aldwin (1999) outlined four differences in patterns of coping responses for individuals dealing with trauma versus the type of coping used to deal with stressors associated with daily life. The first difference entails the perception of loss of control over one's cognitions and behaviors, resulting in the use of more "primitive" coping strategies of dissociation, repression, and denial. Second, individuals who disclose to others as a way of coping with the traumatic event tend to do

better than individuals who do not, although this may be moderated by the response or reactions from others. The third difference noted is that the length of time is greater for coping with trauma, especially if the individual develops posttraumatic stress disorder, which may actually take decades for adaptation to occur. And finally, the coping strategy of meaning making tends to be used more in traumatic situations than with daily stress. This may entail reworking one's cognitive-motivational structures as well as developing a different interpretation of both the event and its context within one's life. Of particular interest to the present study, it is largely through the use of meaning making that the groundwork for posttraumatic growth is set, which is a similar concept to benefit finding (Aldwin & Sutton, 1998; Lieberman, 1992; Tedeschi, Park, & Calhoun, 1998).

The most widely cited theory of coping, where coping is viewed as a process, is Lazarus and Folkman's (1984) Transactional Model of Stress and Coping. This view holds that one's appraisal of an event as benign, threatening, or challenging influences how well an individual copes with a particular stressor. One's appraisal is influenced both by internal factors, such as beliefs and values, as well as by external factors presented by the specific stressor. Coping then involves employing strategies that lead to adaptation. Five general types of strategies have been identified: problem-focused, emotion-focused, social support, religious coping, and making meaning.

Behaviors that fall under the category of problem-solving coping include information seeking, analyzing the problem, prioritizing areas of the problem on which to focus, thinking through various solutions, and taking direct action. Emotion-focused strategies include expressing one's feelings and suppressing emotions to focus more on

problem-solving, avoidance, and withdrawal. The latter two types of emotion-focused coping are associated with poorer outcomes (Aldwin & Revenson, 1987).

Elements of both problem-solving and emotion-focused coping are involved in the next two types of coping, which are seeking social support and religious coping. Asking for advice or emotional support, seeking concrete aid, and praying are all forms of coping in these two categories.

The last type of coping is the least well studied: meaning making. This involves one trying to make sense of and contextualize the event, putting it into perspective and trying to find positive aspects of the problem.

Parents of children with cancer have been found to use all five types of coping strategies. Various research reports have investigated whether these parents differ from parents of healthy children or children with different illnesses, or how the parents' coping strategies differ by gender.

Researchers found that emotion-focused strategies were used more effectively with emotional and interpersonal stressors (Chesler & Barbarin, 1987), were most helpful when the emotion-focused approach came from one's spouse (Morrow, Hoagland, & Morse, 1982), and were used more by mothers than by fathers (Grootenhuis, Last, De Graaf-Nijkerk, & Van Der Wel, 1996; Larson, Wittrock, & Sandgren, 1994; Powazek, Schyving-Payne, Goff, Paulson, & Stagner, 1980; Wittrock, Larson, & Sandgren, 1994). This was also found to be the case in mothers of healthy children (Larson et al., 1994).

Researchers found that parents regularly used problem-focused strategies, including information-seeking, problem-solving, and help-seeking behaviors (Barbarin &

Chesler, 1984); normalizing family life (Martinson & Cohen, 1988); and cognitive attempts to redefine or refocus the problem (Kupst, 1992). Bearison, Sadow, Granowetter, and Winkel (1993) found that parents who externalized factors related to their child's disease tended to use more positive strategies such as humor and support.

Social support has been shown to be a widely used positive coping strategy for both parents (Kupst, 1984, 1992; Kupst & Schulman, 1988; Magni, Silvestro, Carli, & Deleo, 1986; Morrow et al., 1982), although mothers tended to find social support more helpful than fathers did (Larson et al., 1994). Compared to families of healthy children, these findings differ little (Speechley & Noh, 1992). A study by C. Eiser, Havermas, and J.R. Eiser (1995) found that social support was not as helpful as maintaining family integration or communication with medical staff.

Parents have also been found to use religious-coping (Barbarin & Chesler, 1984; Cayse, 1994) as well as meaning-making strategies (Bearison et al., 1993; Eiser et al., 1995; McWhirter & Kirk, 1986; Ruccione, Waskerwitz, Buckley, Perin, & Hammond, 1994).

The research reviewed for this study supports that parents of children with cancer use all types of the common coping strategies widely found in psychological coping research to deal with the stress of their child's illness.

Correlates of Coping/Adjustment

Numerous studies have explored variables related to how well parents of children with cancer adjust to the illness. Major variables examined include cancer type, stage of

disease, family characteristics, social support, environmental factors, and individual or personal characteristics.

Types of Cancer

The effect of cancer type in parental coping has been difficult to determine due to the small sample sizes in most of the studies. However, it is generally believed that children with central nervous system involvement may be at higher risk due to cognitive challenges and, consequently, their parents may have more challenges with which to cope (Kupst, 1994).

Stage of Disease

Parents of children who have relapsed have higher rates of uncertainty and helplessness (Grootenhuis & Last, 1997). Mothers of relapsed children have been measured to have higher levels of anxiety and depression than mothers of healthy children or mothers of children in remission (Grootenhuis & Last, 1997). The time since diagnosis was not predictive of negative emotion (Grootenhuis & Last, 1997), but the physical condition of the child was correlated to parental coping (Kupst et al., 1982; Morrow, Hoagland, & Carnrike, 1981; Spinetta, Murphy, & Vik, 1988).

Family Characteristics

Family cohesion has been positively correlated to maternal adaptation (Stuber et al., 1994) and negatively correlated to maternal depression (Manne et al., 1995). Families with stable relationships reported being able to maintain their usual level of quality of life and adapt well, despite the increased level of stress (Clegg, 1997; Fife, Norton, & Groom, 1987), and mothers showed an improved level of emotional well-being when

communication was rated as open and frequent (Shapiro & Shumaker, 1987). Pre-existing problems in the family has been associated with lower levels of adaptation (Fife, Norton, & Groom, 1987), and concurrent problems with the siblings of the child with cancer contributed to poorer coping (Kupst et al., 1983). Financial security and higher occupational status of the father have both been shown to contribute to more positive parental coping (Fritz & Williams, 1988; Koocher & O'Malley, 1981; Kupst et al., 1983), although paternal anxiety increased with higher levels of education (Mu et al., 2002).

Social Support

Social support for the family has been found to be very helpful throughout the cancer trajectory to parents of children with cancer (Kupst et al., 1983). It has also been related to decreased reports of subjective stress (Barbarin & Chesler, 1984) and to maternal depression (Mulhern, Fairclough, Smith, & Douglas, 1992).

Environmental Factors

Aitken and Hathaway (1993) found that parents who lived greater distances from the hospital (100 miles or more) reported feeling more sad than parents who did not travel as far. In addition, the frequency of hospitalizations of the child has been associated with a decrease in marital quality and perceived support from one's spouse (Barbarin & Chesler, 1986). Positive personal communication and relationships with medical staff has also been associated with improved coping (Barbarin & Chesler, 1984).

Individual or Personal Characteristics

Feeling optimistic about the future and having positive expectations about the course of the illness have been associated with an increased sense of control (Nannis et

al., 1982) and with more positive emotions in both mothers and fathers (Grootenhuis & Last, 1997). Previous effective coping has been positively correlated to adaptation (Kupst et al., 1983), and subjective distress levels decreased when parents felt they could maintain a sense of self-stability and gain a good understanding of the medical care (Blotcky et al., 1985).

Coping and Adaptation as Outcome

Both individual and family/couple variables have been investigated in studies of parents of children with cancer as a reflection of how well they adapt to the stress of this life-threatening illness. The assumption has been made that these parents would show increased levels of distress and more psychiatric symptoms than parents of healthy children, and in some studies this has in fact been supported. Researchers found that sleep disturbances and depression scores were higher for parents of children with cancer versus healthy controls (Magni, Messina, DeLeo, Mosconi, & Carli, 1983; Magni et al., 1986). Mothers were found to be more anxious and fathers showed increased feelings of depression (Brown et al., 1992; Fife et al., 1987). Parents of children who have been recently diagnosed or are currently in treatment showed elevations in scores on measures of psychological distress, such as depression and anxiety, as compared to normative data (Grootenhuis & Last, 1997; Hoekstra-Weebers, Jaspers, & Kamps, 2001; Powazek et al., 1980), but the magnitude was not as great as is seen in people who generally seek help through psychotherapy. Reports of distress in parents show that distress decreases over time, unrelated to intervention strategies (Best et al., 2001; Hoekstra-Weebers et al., 2001; Kazak & Barakat, 1997; Kazak, Stuber, & Barakat, 1998; Kupst et al., 1995).

Family-related variables have been investigated as a reflection of overall adaptation. In several studies, measures of marital distress were elevated in couples of children with cancer, but the divorce rate, compared to the norm, was no greater (Brown et al., 1992; Koocher & O'Malley, 1981; Lansky et al., 1978; Schuler et al., 1985). Family functioning and adaptation studies have shown that most families function as well as families with healthy children in relation to organization, cohesiveness, and flexibility (Barbarin et al., 1985; Blotcky et al., 1985; Horowitz & Kazak, 1990; Kazak, Christakis, Alderfer, & Coiro, 1994; Kazak & Meadows, 1989; Manne et al., 1995).

Overall, parents of children with cancer did not demonstrate high levels of maladjustment or psychopathology and did, in fact, cope well (Gartstein, Short, & Vannatta, 1999; Kupst, 1994; Kupst et al., 2002; Patistea, 2005; Verrill, Schafer, Vannatta, & Noll, 2000). Many of these studies focused on pathology and distress, yet parents frequently identified positive aspects of the experience, without being specifically asked. For example, parents identified feeling positive about support systems, developing new values or attitudes, re-evaluating life goals and priorities, and valuing life more as a result of this experience (Eiser & Havermas, 1992; Greenberg & Meadows, 1991; Grootenhuis & Last, 1997; Peck, 1979). Other parents said that their family was closer (Koch, 1985) and that their marital relationship actually improved (Koocher & O'Malley, 1981; Marky, 1982).

It is interesting to note that, in the multitude of studies that have explored parental coping, data supporting the competence of these parents are strong. Despite having to cope with a multitude of stressors, many parents cope adequately and have reported

growing as a result of this experience. However, very little is known about how the coping and growth actually occur. Research within the field of positive psychology may provide a framework to help understand this positive adjustment. Areas related to benefit finding are reviewed in the next sections, including thriving, mastery, and posttraumatic growth.

<div align="center">Thriving</div>

Thriving is a well-researched concept related to benefit finding with origins in coping literature. Thriving has been defined as a positive physical, mental, and /or social development that occurs when an individual effectively mobilizes personal and social resources in response to a threatening or dangerous situation (Carver, 1998). Thriving has been studied as both a physical and a psychological phenomenon and is associated with greater levels of well-being and quality of life. Eggert Petersen (1997) developed a theory of psychological thriving, which originated from studies of working life. Petersen's theory is based on a sociopsychological interactionist model in which thriving is a result of an individual's interaction with his or her environment. Petersen proposes that the basis for an individual's experience of well-being or thriving is formed by the fulfillment of significant expectations within a particular environment. From this perspective, thriving is seen as an emotional state that increases one's ability to experience and express satisfaction.

O'Leary and Ickovics (1995) contrasted the concept of thriving to resilience, saying that thriving is more than a return to equilibrium and that it is "value-added" in that challenge is seen as the impetus for growth and greater well-being; thriving is an

adaptive response to stress. Carver (1998) described individuals who thrive as those who come to function at continuing higher levels than before the stressful event—a "better-off-afterward" experience.

Certain resources and processes have been shown to promote thriving. These include personal qualities such as positive cognitive reframing (Bower, Kemeny, Taylor, & Fahey, 1998; Calhoun & Tedeschi, 1998; Janoff-Bulman & Berg, 1998; Neimeyer & Levitt, 2001); benefit finding (Affleck & Tennen, 1996; Davis et al., 1998); social status (Adler, Epel, Castellazzo, & Ickovics, 2000); social support (Calhoun & Tedeschi, 1998; Carver, 1998; O'Leary, 1998); spirituality and religious beliefs (Calhoun, Cann, & Tedeschi, 2000; Calhoun & Tedeschi, 1998; Myers, 2000; Park, 1998; Ramsey & Blieszner, 2000); and supportive psychotherapy (Saakvitne, Tennen, & Affleck, 1998).

The research on thriving conceptualizes benefit finding as a process one engages in that contributes to a challenging experience. It may be that, in order to thrive in a stressful situation, one must find benefit in the experience.

<div align="center">Mastery</div>

Another concept that is similar to benefit finding is the theory of mastery, as proposed by Younger (1991). Younger defines mastery as a "human response to difficult or stressful circumstances in which competency, control, and dominion are gained over the experience of stress. It means having developed new capabilities, having changed the environment, and/or reorganized the self so that there is a meaning and purpose in living that transcends the difficulty of the experience" (p. 81). Younger postulates that the

human response to stress is basically existential in nature; that is, an individual's philosophy of life greatly influences the response to a stressful situation.

Additionally, Younger (1991) delineates intrapersonal as well as interpersonal characteristics that define mastery. Intrapersonal characteristics involve the way the person experiences himself or herself that include (1) a sense of perceived or actual control over the situation that created a sense of vulnerability; (2) a plan to help keep this situation, or one similar to it, from happening again; (3) feeling good about oneself again, and (4) having alternative sources of satisfaction for what has been lost. These personal resources serve to create a sense of a higher quality of life than prior to the stressor.

The interpersonal characteristics relate to the resources within the person's relationships with others. An increased sense of community with others as well as stronger family relationships coupled with a greater sense of understanding about life experiences result in one being more compassionate toward others.

Conceptually, mastery contains the following elements: certainty, change, acceptance, and growth. Younger (1991) describes these four processes as part of the cycle that results in mastery over a stressful situation. All four begin early in the process and overlap, influencing the emergence of the other processes. Certainty refers to one's ability to have a particular view about the situation that is relatively free of troublesome doubts. It is a view that is realistic but hopeful and enables the individual to sustain an intact view of the self and the world. After certainty occurs, the individual engages in the processes of change and acceptance. Change refers to the ability to directly influence the stressful situation or to affect the resources in the environment in order to diminish the

impact of the stressor. In dealing with the stressor, one also comes to an acceptance of the events as true and normal, acknowledging the losses associated with the event while choosing to move forward, allowing hope to return and developing new attachments.

According to Younger (1991), as the individual moves through the processes of certainty, change, and acceptance, growth occurs. Growth is a state in which new competencies are attained, followed by a sense of feeling stronger with a more purposeful direction in life. The individual develops a more meaningful approach to life and, often, a creative outgrowth springs from the stressful experience itself.

Mastery, then, is an outcome of successfully coping with a crisis or difficult situation. A concept that is a "special case of mastery" (Younger, 1991, p.77) and deserves mention is health-within-illness, a nursing concept developed by Moch (1989) from her research with women diagnosed with breast cancer. The concept of health-within-illness is based on the premise that illness is a potential source for growth that involves an increase in the meaningfulness of life through an increased sense of connectedness with the environment and self-awareness that occurs only when one's health is compromised (Moch, 1989). Moch developed this conceptual definition over 12 years, proposing four components that comprise the definition: (1) the opportunity of chance provided by the illness experience, (2) increased meaningfulness, (3) connectedness/relatedness, and (4) awareness of self. The latter three components reflect the same three prominent areas found within the studies of benefit finding: perceptions of personal growth, the strengthening of relationships, and a change in life's priorities and personal goals (Tennen & Affleck, 2002).

Perhaps benefit finding may be considered an aspect or part of the process that occurs in order to maintain or achieve health-within-illness. If one is able to experience the emergence of benefits in an illness experience, perhaps "health" or healing is an outcome. Benefit finding implies well-being at a level untouched or unaffected by the illness. One is able to remain whole, or healed, within a challenging situation, perhaps even transcending aspects of the compromised state.

Posttraumatic Growth

Posttraumatic growth is a concept put forth by Tedeschi et al. (1998), who began working on its conceptualization in the early 1980s. Posttraumatic growth has also been referred to as adversarial growth, transformational growth, and positive psychological change. This concept initially came from coping research and was presented as a coping strategy or mentioned as an aside when reporting the multiple negative outcomes observed following adverse events. However, in their work with trauma victims, Tedeschi et al. observed the transformative power of trauma, which could be traced back to early philosophical writings, and proposed it to be a fundamental human experience. They view this concept as both a process and an outcome that originates in the cognitive processing of a seismic or traumatic event. They believe that the experience with a crisis makes individuals question their basic assumptions about current experiences and expectations of the future, creating great anxiety. As individuals cope with this anxiety, some are able to not only return to their previous level of functioning, but actually grow and benefit as a result. In order to explore this phenomenon, Tedeschi et al. have pursued

ways to document what they have observed, developed tools to measure posttraumatic

growth, and are working to generate a theory to explain it.

<div style="text-align:center">*Concepts Related to Posttraumatic Growth*</div>

Variables related to posttraumatic growth are resilience, sense of coherence, and

hardiness. These variables are more closely seen as individual characteristics or traits but

are influential in the conceptualization of posttraumatic growth.

Resilience

The research on resilience was initially conducted with high-risk children

(Werner, 1989) after observing that some children grew up to lead productive and

successful lives despite living in extremely difficult family situations such as poverty,

poor education, alcoholism, marital discord, and mental illness. Although the majority of

children from these stressful environments suffered behavioral or learning problems later

in life, about one third of the children were found to be resilient and had achieved

relatively successful lives. Further research identified cognitive abilities, effective social

skills, and adaptive coping strategies as contributing to a greater sense of self-sufficiency

and self-esteem in these resilient children (Garmezy, 1985; Rutter, 1987). Aldwin and

Sutton (1998) suggest that the same factors that contribute to resilience in children may

also contribute to posttraumatic growth.

Sense of Coherence

Antonovsky (1987) used the term "sense of coherence" to refer to numerous

personality traits that certain individuals possess that helped them deal well with stress.

His original research was with women survivors of the Holocaust, who faired

exceptionally well despite their horrendous treatment. From his research, Antonovsky

delineated three interrelated components that comprised a sense of coherence:

comprehensibility, manageability, and meaningfulness. Comprehensibility refers to one's

ability to find a sense of predictability in stressful situations. Manageability is having the

sense that one's resources are adequate to face the demands of the situation, and

meaningfulness refers to the ability to find meaning in life and to accept the challenges

associated with daily living. Studies that have correlated sense of coherence to various

outcomes have shown a sense coherence to be associated with improved physical and

mental health (Calhoun & Tedeschi, 1998).

Hardiness

Kobasa first conducted studies in the 1970s with executives to find out why some

of these individuals were less vulnerable to the effects of stress. She coined the term

"hardiness" as a relatively stable personality state, formed early in childhood, which leads

one to have a set of beliefs about oneself and the world and how they interact (Kobasa,

1987; Kobasa, Maddi, & Kahn, 1982). Kobasa found that the messages stress-hardy

individuals received as children could be focused in three general areas: (1) They were

focused on reward, not punishment, thus building a sense of commitment rather than

alienation; (2) the tasks they were given were relatively difficult so, once accomplished,

provided feelings of control rather than powerlessness; and (3) they were encouraged to

view changes as full of possibilities, which led them to approach stress as a challenge

rather than a threat. The three personality traits, which were seen in stress-hardy

executives, were those of commitment, control, and challenge. In later studies, using the

Hardiness Scale she developed, Kobasa found that, in addition to these individuals having a positive perception of stress, they had better physical health, stronger immune systems, and only half of the illnesses experienced by their counterparts who did not have these traits.

Areas of Posttraumatic Growth

There are three main areas in which individuals reflect posttraumatic growth: changes in perception of self, changes in interpersonal relationships, and changes in philosophy of life (Tedeschi & Calhoun, 1995). Growth in the area of self-perception is reflected by seeing oneself as a survivor rather than as a victim of trauma, allowing individuals to recognize their strengths and sense of being unique. Additionally, growth is reflected not only by an increased sense of self-reliance and self-efficacy, but also by an awareness of increased vulnerability. Together, these views contribute to a recognition that life is precious and often creates a shift in priorities. Posttraumatic growth also allows one to reach out for and appreciate social supports that one may not have used prior to experiencing a stressful event.

Growth in the area of interpersonal relationships is reflected in the ability to be more emotionally expressive and compassionate to others. Self-disclosure and emotional expressiveness have been correlated with positive physical and mental health outcomes (Pennebaker, 1995). Additionally, the experience with a highly stressful event provides one with emotional knowledge that one often feels compelled to share with others experiencing a similar event. When an individual experiences the universality of

suffering on a deeply personal level, there is often a sense of feeling more connected with others and a desire to help others through sharing of one's own feelings.

The third area in which growth following adversity is seen is in one's philosophy of life. One change in this area is an increased appreciation with life, with a shift in priorities to reflect this view. The shift may include enjoying the "little" things in life, spending more time with family, and letting go of unnecessary responsibilities to allow for a simpler, more meaningful life. It also includes developing an awareness of meaningfulness in the larger, existential sense that questions the purpose in living. A change in one's philosophy of life often also entails developing a deeper spiritual life as well as wisdom about one's life. Spiritual growth is seen in a stronger connection to something greater than oneself that grows out of the struggle with adversity. It may also be a return to or greater appreciation for one's traditional religious belief system. Wisdom is described as a culmination of the previously described experiences, an increased perspective on life, including skills of balance, judgment, and communication (Kramer, 1990). Wisdom involves the recognition that one's life may have been enriched by traumatic events, being able to integrate feelings of distress with an appreciation for life.

The concepts of thriving, mastery, and posttraumatic growth are similar and seem to have the common experience of benefit finding as an aspect of their occurrence, although it may not be specifically stated as such. In the following section, benefit finding is reviewed to further explore what is known specifically about this concept, as well as the gaps and areas needing further research.

Benefit Finding

Benefit finding has come to be a widely used construct in the literature regarding positive coping (Tennen & Affleck, 2002). People who have had a wide array of tragic personal occurrences report receiving benefits from their experience, most often including perceptions of personal growth, stronger personal relationships, and increased prioritizing of life goals (Affleck et al., 1987; Affleck, Tennen, Pfeiffer, & Fifield, 1988; Bulman & Wortman & Silver, 1987; Cruess, Antoni, & McGregor, 2000; Mohr, Dick, & Russo, 1999). Benefit finding has been positively associated with emotional well-being; however, most of the studies have examined positive adaptation associated with benefit finding within the traditional paradigm of psychopathology. The research has investigated benefit finding as it has been associated with decreases in symptomatology, frequency of diagnostic indicators for psychopathology, risk of negative outcomes, and mortality.

Additionally, most of the research designs used to investigate benefit finding have been cross-sectional, measuring benefit finding at the same time as adaptational outcomes, which can point to correlations between benefit finding and emotional and physical well-being, but cannot provide information about whether benefit finding anticipates positive health outcomes. In conducting the literature search for the present study, I found 65 citations under the search term "benefit finding," 37 of which were research articles related to 26 different studies. The majority (18) of these studies included patients with cancer (12 studies examined patients with breast cancer, 6 examined patients with other forms of cancer); five studies investigated caregivers and/or

patients with multiple sclerosis; five studies dealt with the experience of grief or loss; four studies examined patients with other medical illnesses, including HIV; two studies involved people who had experienced nonmedical crises; and three studies related to parenting a child with an illness or disability. A qualitative or mixed-methods design was used in 5 of the 26 studies, mostly through written narratives with analysis of major themes.

Twelve studies investigated the correlation between benefit finding and well-being. Results from 11 of these studies showed a positive correlation between benefit finding and positive adaptations such as adjustment (Davis et al., 1998; Michael & Snyder, 2005; Mohr et al., 1999; Pakenham, 2005; Rini, Manne, & DuHamel, 2004); life satisfaction and positive affect (Pakenham, 2005); social support and positive coping (McCausland & Pakenham, 2003; Sakaguchi, 2002); decreased suffering, depression, and distress (Carver & Antoni, 2004; Katz, Flasher, Cacciapaglia, & Nelson, 2001); and religious activity (Urcuyo, Boyers, & Carver, 2005). Paradoxically, one of the studies found a positive correlation between benefit finding and negative affect (Tomich & Helgeson, 2004) and another found a positive correlation between benefit finding and increased anger and anxiety (Mohr et al., 1999). Additionally, one study found no correlation between benefit finding and life satisfaction (Pakenham, 2005) and another found no correlation between benefit finding and depression (Mohr et al., 1999).

Several studies investigated coping strategies that could predict an increase in benefit finding. Luszczynska, Mohamed, and Schwarzer (2005) found that certain resources (self-efficacy and social support) and coping strategies predicted aspects of

benefit finding in cancer patients. McGuffey (2001) reported that religiousness increased benefit finding and lower cortisol levels in HIV-positive men. In two other studies, researchers reported that demographic variables have an effect on benefit finding: Fortune, Richards, and Griffiths (2005) and Lechner, Zakowski, and Antoni (2003) found that younger age at diagnosis correlated positively with benefit finding in women with breast cancer. Lechner et al. (2003) also found that the stage of the disease in cancer patients correlated with benefit finding in a curvilinear fashion, with individuals with Stage II disease having significantly higher scores on the benefit-finding scale than those with Stage I or IV. Time since diagnosis or treatment status was not correlated with benefit finding.

Groups of researchers at the University of Miami conducted interventional studies to investigate the effects of a Cognitive Behavioral Stress Management (CBSM) program on benefit finding, serum cortisol, and cellular immune functioning. McGregor, Antoni, and Boyers (2004) published findings that showed an increase in scores on the benefit-finding scale and in lymphocyte proliferation in women with breast cancer who had participated in a 10-week CBSM intervention. Findings from a study by Antoni, Lehman, and Klibourn (2001) showed that the same CBSM intervention reduced depression and increased benefit finding and generalized optimism, both of which remained significantly higher at a 3-month follow-up period. Additionally, Cruess and colleagues (2000) found that women had who attended the CBSM group had lower serum cortisol levels and that cortisol was mediated by increases in benefit finding.

Two other studies also suggest that the perception of benefits may be influenced by interventions. King and Miner (2000) found that college students who wrote about benefits they experienced from a negative life event had fewer visits to the student health center over the following 5 months compared with controls. Similarly, Stanton and Danoff-Burg (2002) found that women with breast cancer who wrote about positive thoughts and feelings related to their experience had fewer medical appointments than the control group for cancer-related problems.

Summary

As evidenced in the research reviewed in this chapter, benefit finding has been conceptualized as selective appraisal, a coping strategy, and a personality characteristic. Research findings also suggest that benefit finding may be viewed as a reflection of growth or change, an explanation of one's temperament, a temporal comparison, or a manifestation of implicit change theory (Tennen & Affleck, 2002). Perhaps the greatest challenge in researching the construct of benefit finding is the lack of agreement in how the construct is conceptualized. By conducting a grounded theory intended to explore in depth the experience of benefit finding in parents of children with cancer, the aim of the present study was to develop a comprehensive theoretical model that will more fully account for the range of moderating and mediating influences involved in the process of benefit finding. Thus, the following questions were explored:

- When is benefit finding most likely to occur?

- Under what circumstances does benefit finding emerge?

- What facilitates or hinders the experience and expression of benefit finding?

- Is benefit finding experienced or expressed differently by mothers and fathers?

- How are the experiences defined?

These questions were asked "of the data" that was gathered from interviews conducted with parents of children with cancer in order to provide a comprehensive understanding of the concept of benefit finding from the participants themselves.

CHAPTER 3

METHOD

Grounded theory (Glaser, 1978, 1998; Glaser & Strauss, 1967) was the method
used to investigate the following research question: What is the process by which parents
of children with cancer come to find benefit within this experience?

Rationale for a Qualitative Approach: Grounded Theory

Given the gaps in what is known about the experience of benefit finding in
parents of children with cancer and to deepen the understanding of the benefit-finding
process, a qualitative design was chosen to explore this process and the context within
which this phenomenon occurs. Because the construct of benefit finding is considered a
dynamic process and because the current study focused on how benefit finding is
experienced, I chose grounded theory for the study's method. The goal in using grounded
theory was to obtain a deeper understanding of the many facets of the experience of
benefit finding and to develop a conceptual model to organize and depict the constructs
and structures that arise through the process of constant comparison analysis.

Grounded theory method is based on the theoretical assumptions of symbolic
interactionism and assumes that individuals create meaning from events within the
context of the environment in which they interact. This environment may include the

36

family unit, the clinic environment, and the interpersonal environment created between the researcher and the participant. Symbolic interactionism assumes that all experiences are bidirectional; that is to say, the experience of the parents both influences and is influenced by extrinsic factors such as socioeconomic strains and resources associated with families of child-rearing age, as well as by cultural and gender-specific expectations related to parenting. Because these experiences are socially dynamic, grounded theory offers a strong organizational method for identifying the main concern or the Basic Social Psychological Problem of the participants and in what patterns of behavior they engage (identified as the Basic Social Psychological Process) to resolve this main concern (Glaser, 1998).

<div align="center">Participants</div>

The participants for this study were parents of a child diagnosed with cancer. Efforts were made to have equal numbers of fathers and mothers. The inclusion criteria were that parents were able to communicate in English and had a child diagnosed with a first occurrence of any type of a malignancy currently being treated at the hematology/oncology clinic in the maintenance phase of treatment. Only English speakers were included because of the degree of self-disclosure and complexity involved in the interview process; unnecessary frustration may have arisen for both the participant and the researcher if translation was necessary. It is understood that the English-speaking criterion may have excluded parents who would otherwise have been potentially significant resources in providing insights into cultural dimensions of the concept of benefit finding, and this was a limitation of the study. In addition, by including children

with any type of cancer, there was a range of prognoses to which parents may have responded with a variety of emotions. By exploring the experience of benefit finding in situations where parents had perhaps different degrees of hopefulness, the experience of benefit finding was clarified through these influencing factors.

All children were in the maintenance phase of treatment so as to give the parents time to get through the shock and disbelief of the initial diagnosis. In the early stages, much of the parents' energy is often focused on learning about the treatment, developing trust in the staff, and becoming familiar with the treatment protocol, routine of care, and other "tasks" associated with becoming a parent of a child with cancer.

Parents of children who had relapsed were excluded because the experience of relapse is intense and often accompanied by additional tasks and stressors, requiring parents to make additional difficult decisions during an already stressful time.

All parents, when asked, stated that they had found benefits in their experience of having a child diagnosed with cancer. Flyers that described the aim of the research were distributed in the clinic, asking parents who were willing to talk about their experience of benefit finding to contact me (see Appendix A). Participants were chosen through the use of theoretical sampling, which was purposive in nature and was used to increase the diversity of the sample. It was intended to search for and illuminate different properties or characteristics of a certain theme or relationships among themes that emerged during the initial interviewing process. This process included both seeking out new parents and re-interviewing parents to follow up on emerging themes. The process is discussed in more detail in the section titled, "Data Generation."

Research Site

The setting for this study was the outpatient pediatric hematology/oncology clinic located within a large urban teaching hospital in the southeast region of the United States. This clinic sees approximately 60 to 70 newly diagnosed children each year for treatment of cancer. The staff of the clinic consists of five physicians, three advanced practice nurses, several registered nurses, a social worker, chaplain, and a child life specialist. The most commonly diagnosed type of cancer is acute lymphocytic leukemia, followed by brain tumors and lymphoma.

I discussed access to the setting with several of the staff with whom I was familiar, from both personal and professional contacts. A protocol for gaining access to the setting was negotiated with the appropriate personnel so as to ensure confidentiality and to create a minimal amount of disruption of the normal flow of activity. I met with the staff at the monthly department meeting and reviewed the research proposal. The director of the clinic gave me approval to conduct the study.

The majority of the interviews were conducted in a private consultation room located adjacent to a large, open treatment area. The consultation room was also within close proximity of all private treatment rooms. One of the interviews was held in a private treatment room with the child nearby, watching video games. The location allowed the parents to remain in close proximity to their child. The staff members were informed of the meeting time and place so they could quickly locate the parent, if needed.

Role of the Researcher

My own interest in this study's topic was both personal and professional. My professional interest originated from my working with children in my first nursing job on a pediatric unit and, later, with children and adolescents in a psychiatric hospital. I obtained my master's degree in child and adolescent mental health nursing and became certified as a clinical nurse specialist in psychiatric mental health nursing. I have worked in a variety of inpatient and outpatient settings conducting individual, group, and family therapy from a systems perspective. My interest expanded to include mind-body interventions, and, after receiving training from the Harvard Mind-Body Medical Institute, I incorporated stress-reduction and positive coping aspects into my work.

On the personal level, my interest came from having had a child with cancer. My first child was diagnosed with a rare form of leukemia shortly after his first birthday in 1987 and passed away 5 years later. I understand the suffering and growth that can accompany this experience and wanted to explore others' experiences in a professional and systematic way.

My experiences contributed inherent strengths and limitations. Professionally, my strengths were that I am a skilled clinician; I have received and provided many hours of clinical supervision and practice in the delicate areas of developing trust, making empathic connections, listening with a "third ear," and observing nonverbal communication. Personally, having experienced 15 years ago what the participants were

currently experiencing may have helped me to be more attuned to areas that were important to explore and clarify.

The potential limitations and biases that must be considered were that my own memories were recalled during some of the interviews. I needed to be sensitive to the parents' desire to tell their stories and experiences, allowing for all degrees of variability. How much of my own experience I chose to share with participants depended on the situation and was included in the memos made throughout the study.

Data Generation

A number of different methods were employed in generating data. The majority of the data was obtained through interviews, with additional data generated through participant observations, documents, field notes, literature reviews, and a personal journal. Using multiple sources of data provided a breadth of information, which was constantly compared and analyzed, allowing me to explore and clarify the emerging themes and hypotheses from many angles.

Prior to gathering data, the study was approved by the Virginia Commonwealth University Institutional Review Board (see Appendix B). All participants signed an informed-consent form (see Appendix C).

Interviews

Structured and semistructured interviews were conducted with the parents. Interviews were conducted using a general outline but were largely unstructured and included a retrospective account in order to focus on identifying processes (Morse, 2001). All but one took place in a private room located near the nurse's station in the clinic. The

interviews were tape recorded with the participant's consent, which allowed for review
and transcription to ensure the data remained grounded in the words of the participants.
The interviews began with gathering general demographic information (see Appendix D),
then followed with a general question about the participant's experience with benefit
finding. Questions became more specific as the interview progressed, in order to clarify
concepts and incrementally build the strategies and processes from which the theory
materialized. The interviews included the following questions:

- Some parents of children with cancer have said that, although the experience has
  been frightening and stressful, they have also found benefits in this experience.
  Can you tell me about your experience of finding benefit during this time?

- Feeling [support of family and friends/increased connection to God or a Higher
  Power/self-confidence/etc.] has been identified as a benefit by some parents. Can
  you tell me how your experience of this feeling is related specifically to dealing
  with your child's cancer?

- How do you think this came about?

- Was there any part of this that was surprising or unexpected?

- Were you aware of doing anything different to help it along?

- Do you think it would have occurred had you not experienced this crisis with your
  child?

Such questions were intended to explore the process specifically related to
parents' experience of having a child diagnosed with cancer and to unearth the subtle
aspects of themes and their relatedness. During the interviews, I made brief notes to

identify key words or concepts as they emerged. I did not make lengthy notes because doing so might have been distracting and possibly impeded the natural flow of conversation.

Semistructured Interviews

Semistructured interviews were conducted as the opportunity arose, after consent had been obtained. These brief interviews occurred in the waiting area, hallways, or patient rooms and were not tape recorded; rather, they were recorded in field notes after the interactions took place.

Observations

Observations were made during the interviews as well as in unstructured interactions within the clinic in an effort to record the mutuality of influence within the context of the clinic environment. Initially, observations were made of the clinic population as a unit and treated as a whole, which is known as "getting in the field" (Glaser & Strauss, 1967). This approach gave me a feel for the overall "zeitgeist" of the clinic. Observations regarding facial expressions, eye contact, and initiation of communication were recorded in field notes to add depth to the participants' responses.

The strategies of prolonged engagement and persistent observation were used in order to increase the scope and depth of the data (Lincoln & Guba, 1985). For the current study, I remained in the field for 12 months in order to allow time to become oriented to the setting, to develop trust both with the staff and with the participants, and to generate sufficient data.

Field Notes

I recorded hand-written field notes immediately after a period of observation, document review, or interview. These notes included recordings of behaviors, time and place, events to place the notes in context, and specific words or phrases that were particularly meaningful, as well as my impressions of the interaction. The notes were brief and served as an aid to help me recall particulars.

Literature Reviews

As data were generated and analyzed, literature was reviewed for research relevant to the experience of benefit finding and to guide additional questions in areas that may have needed deeper investigation or to support or negate relationships among emerging themes. This process was a secondary review of literature and was used to compare the current findings to other data relevant to the substantive area.

Personal Journal

I kept a personal log or journal about my feelings and thoughts that arose throughout the data collection and analysis. The journal was intended to help me increase awareness of my values and reactions in an effort to decrease the possibility of making erroneous assumptions.

Theoretical Sampling

Theoretical sampling is a rigorous methodology used for data generation and analysis. Through its application in the current study, I enhanced the credibility of the study by demonstrating consistency, applicability, neutrality, and truth value. Theoretical

sampling is a process that entails collecting, coding, and analyzing data simultaneously in order to direct the researcher toward additional data sources to develop the theory as it emerges. As data are coded, the results lead the researcher to ask, "Where next?" and "What is this for?" and "Why?" This approach helped me to further clarify the theoretical aspects of the codes, their properties, and how they were related. Comparisons were sought to evaluate the emerging conceptual framework, which helped to focus and delimit the further collection and analysis of data. In this way, data collection was kept to a minimum because I gathered only data that were relevant for the development of new categories and properties. When no new information came forth, data saturation was achieved. The constant comparison that took place throughout the process of theoretical sampling helped to keep the study's focus on the meaning of the data and of the theoretical connections.

Data Management

Interviews were mechanically recorded and transcribed. I listened to the tapes multiple times and made notes of key words and phrases. Field notes were used to help provide context and record subtle visual cues that were not conveyed verbally. Both the notes from the interviews and the field notes were hand-written, and memos were recorded alongside the data. I used only participants' initials on the pages, and I dated and numbered each interview. All data were stored at my home in a locked file cabinet.

Data Analysis

Data were analyzed by the constant comparative method, as outlined by Glaser and Strauss (1967). This method involved going back and forth (constantly comparing)

between data and the field to gather information about a particular concept that was then coded into categories, properties, and hypotheses. The steps involved in this procedure occurred simultaneously and entailed both inductive and deductive research methods (Glaser & Strauss, 1967). Inductively, the theory arose from specific observations and data generated from the interviews. The theory was then verified in further interviews in order to develop predictions based on general principles, in the deductive perspective.

Initially, the focus was on generating data. The initial interviews began with questions from the interview guide focusing on the types of benefits the participants identified. Participants were then encouraged to talk about how they came to find benefits, related to time frames and specific incidents or experiences that influenced benefit finding. The interviews were audio taped to allow for an easy exchange of information. Field notes were recorded immediately following the interviews, noting impressions of the information obtained and the relatedness of emerging themes. Next, the interviews were transcribed. As I transcribed and read the interviews, I asked questions about the data, such as, "What is going on here?" and "What is the meaning to the participants?" and "What are the larger issues?" This step of open coding allowed me to identify the initial themes by highlighting words on a line-by-line basis, emphasizing common words, and color-coding words or phrases that were similar. Each typed transcript was placed in an individual folder, and I made hand-written notes or memos directly on the transcripts and on the outside of the folder regarding words and phrases that came up frequently.

The first two to three interviews revealed similar types of benefits identified by the participants as well as the conditions that influenced their ability to find benefits. Through selective coding, I was able to identify common themes reflective of the process. The next several interviews focused on exploring and clarifying these commonalities, thus identifying the properties of the categories.

As new data were collected, they were compared to the existing data and, through axial coding, the focus shifted to developing hypotheses about the relationships among the concepts. It became clear that categories reflected the benefits, the intervening conditions, the main problem or concern, and the strategies that the participants used to cope with the problem. A systematic theoretical framework was formed, which explained the process that was occurring in this particular area.

Glaser and Strauss (1967) define four specific stages to the constant comparative approach: (1) comparing incidents applicable to each category, (2) integrating categories and their properties, (3) delimiting the theory, and (4) writing the theory. The four stages build upon the previous stages but are not mutually exclusive, and each stage remains in operation concurrently until the analysis is complete.

Comparing Incidents Applicable to Each Category

I began by looking at the data and by listening closely and coding each incident into as many categories as possible, allowing categories to materialize as data presented itself. This was done by noting categories in the margins of the text, as I saw them appear. Incidents were constantly compared to one another while coding them for categories, noting similarities and differences. If similar, the incidents were grouped

under one category, and, if they differed, a new category was created, allowing for a range of categories and properties.

Through this process, theoretical properties of categories were generated. Properties are conceptual aspects of a category, whereas categories are able to stand alone as a conceptual element of the theory. Properties describe the category, its dimensions, and conditions that influence its strength, as well as consequences and relationships to other categories.

As categorical coding proceeded, I recorded theoretical ideas through the use of memoing, which is perhaps the most important aspect in this process because it is the principal technique for recording emerging relationships between categories. Memoing began in the first stage and continued throughout, with the memos forming the hypotheses or propositions within the theory.

Streubert and Carpenter (1999) listed three types of memos: (1) code notes, which describe concepts representing processes associated with behavior or meaning; (2) theory notes, which summarize the researcher's ideas about what is going on overall; and (3) operational notes, which pertain more to practical matters. Through the process of data generation and analysis, I began to recognize relationships among categories and their properties.

Integrating Categories and Their Properties

As I moved from comparing incident to incident to comparing incidents to properties of a category, the relationship among properties was identified, becoming integrated as a unified whole. Additionally, categories themselves began to appear

related, creating the need to make some theoretical sense of each comparison. This "theoretical sense-making" entailed recording concepts and describing the relationships among them. These relationships formed the basis for the hypotheses or propositions, linking conceptual processes to one another.

In order to clarify these categories and their properties, I focused my data gathering in a more purposive manner, through theoretical sampling. As questions arose about the data and how to theoretically connect what appeared, I sought out additional information to fill in gaps and strengthen the emerging theory. This was done with selective interviews and review of literature, training in on theoretical relatedness and dimensions of categories and properties.

Theoretical sampling also enabled me to focus data collection and analysis so that the same data were not collected over and over, based on the same questions. Through theoretical sampling, categories and their properties became saturated; no new data came forth related to that area. This created the opportunity for new questions, adding to the depth and richness of the emerging theory.

Delimiting the Theory

As the theory developed, I looked for underlying uniformities in the categories and properties, allowing higher-level concepts to subsume or make generalizations about their connectedness. In this way, the theory was delimited—non-relevant properties were removed, categories became clearer and saturated, and some generalizations were formed while remaining grounded in the data. This helped me to focus on only data that were relevant to the categories, establishing theoretical criteria to clarify related categories and

properties. Questions such as, "Is this a condition or a context?" and "Is it a matter of degree or dimension?" were asked of the data to delimit the variables.

After a time, a core category became evident, one that had the highest frequency of mention and was connected to most of the other emerging categories. Categories were organized around the core category, clarifying the properties and their relatedness until saturation was achieved. I aimed to develop an integrated product with the core category as the main hub.

Writing Theory

The integrated product was an analytic framework presented as a systematically derived substantive theory. A substantive theory, as this study aimed to uncover, refers to a way of explaining, predicting, and interpreting what is happening (a process) in a particular area of inquiry that is relevant to those involved. In this study, that was to explain, predict, and interpret how benefit finding occurs in parents of children with cancer.

To start writing the theory, the coded data as well as detailed memos that represent the major themes of the theory were used for the development of concepts and propositions. Memos related to each category, concept, or proposition were collated and summarized and, once again, compared to the original data to validate the major theoretical propositions and concepts. The theory was written conceptually, by making theoretical statements about the relationships among concepts, not the individuals themselves, and was presented as an integrated set of hypotheses, not findings.

Methodological Rigor

Rigor for this study was established using the procedures based on Glaser (1978, 1998), Glaser and Strauss (1967), and Lincoln and Guba (1985). The latter proposed four criteria by which to judge the trustworthiness of qualitative research. The first criterion is truth value, which refers to the credibility of the research. It is achieved when the study is immediately recognizable; that is, it describes and accurately represents the participant's experience in the context of the environment. Glaser and Strauss (1967) suggested that the processes of theoretical sampling, using multiple data sources and the constant comparison of these sources, establish credibility. Through the use of constant comparison, the researcher continuously goes back to the data sources to ground the relationships to the data, thus keeping the theoretical propositions credible. I used the expertise of experienced researchers, namely the experienced qualitative researchers of the committee, to assess the procedures and theory development for logical conceptualizations.

The second criterion relates to what is referred to as transferability, or "fittingness." Transferability is determined by how well the findings can "fit" into contexts outside of the study situation (Sandelowski, 1986). This occurs when the audience for whom the research is intended views the findings as meaningful and applicable in terms of their own experiences. Transferability also relates to how well the theory seems to fit the data from which it has developed.

To address transferability, I described the setting and conditions under which the data were collected vividly and with clarity, as well as included description of the

characteristics of the participants to help identify similarities and differences in subsequent studies. Data analysis was reviewed by peers who are familiar with grounded theory research, which helped prevent assumptions. If, through careful analysis, the data accurately reflect the experience of these participants, then it is more likely that the results may be transferable to other groups, such as families experiencing acute, potentially life-threatening illnesses other than cancer in their children.

The third criterion put forth by Lincoln and Guba (1985) is consistency. Consistency relates to reliability/replicability in the quantitative paradigm and is also referred to as dependability or auditability (Sandelowski, 1986). It is important to be able to assess the merit of a study, to ensure that the findings could be repeated, and that the steps have been clearly outlined. This assessment is known as a "decision trail" and must be described in such a way that another researcher could arrive at a comparable conclusion given the researcher's data, perspective, and situation (Sandelowski, 1986). The decision trail was done as the procedures for the current study were carefully described and followed. Memos were available for review and included notes taken at the moment of the interview/observation, expanded field notes, methodological notes, and a running record of analyses. I used two peer reviewers, who were members of my committee. Both are experienced qualitative researchers, specifically in the area of grounded theory method. A careful log was kept of the categories and how they were derived, which was shared with the peer reviewers at meetings. I met with one of the peer reviewers more frequently in the beginning of the data generation process, and then only as needed, to review notes that helped determine agreement of major categories.

The final criterion, neutrality, refers to the objectivity of the study, sometimes referred to as confirmability. Confirmability has to do with how well the findings represent the experience of the participants and the setting and not the perspectives of the researcher (Lincoln & Guba, 1985). Several participants were asked to read the final results and agreed that the model accurately reflected their experience of benefit finding. This approach assisted the investigator to achieve credible representation of the participants' experience.

Glaser (1978) addressed the issue of rigor though four criteria as applied to grounded theory research: fit, relevance, work, and modifiability. In looking at fit or validity of a study, one is looking to see that the concepts represent the pattern of data it purports to denote. The categories must fit the data, which is achieved through the constant comparison of data to data, data to categories, and data to theory. The concepts and categories that emerged in the present study are described in the findings and supported by quotes from the participants, reflecting the fit of the model.

Relevance refers to the ability of the concepts to reflect what is actually going on and whether what is recorded is really what is important to the participants. The notion of the Basic Psychosocial Process was developed in grounded theory to account for a considerable portion of the action; that is, the core variable that integrates all other categories of the process used by the participants to resolve their main concern (the basic psychosocial problem). Findings were reviewed with the participants to ensure that their main concerns were accurately reflected in the developing model.

Third, the emerging theory must work. That is to say, the emerging theory should be able to explain what happened, predict what will happen, and interpret what is happening in the area of substantive inquiry (Glaser, 1978). In sharing the theoretical model with the participants, parents' feedback supported the findings.

Finally, Glaser (1978) explained that the theory must be modifiable through the process of constant comparison to include new incidents that work, fit, and are relevant. The main aspects of the theory remain constant but are influenced by emerging data, thus allowing applicability to other substantive areas. The categories and subcategories that emerged through the constant comparative analysis were expanded and clarified, creating a theoretical model reflective of the process of benefit finding in parents of children with cancer. Although the theoretical modal may be applicable to parents of children with other illnesses or conditions, further research would be necessary to broaden the applicability of the model.

<div align="center">Summary</div>

Over a period of one year, 15 parents shared their stories related to their experience of finding benefit through dealing with their child's cancer. Through constant comparison of their narratives, a theoretical model was developed, reflecting this process. The findings are described in the following chapter.

CHAPTER 4

FINDINGS

The purpose of this study was to develop an understanding of the process of
benefit finding in parents of children with cancer. Based on study findings, a theoretical
model was developed. Grounded theory methods were used to address the purpose.
Semistructured interviews were conducted from October 2006 through October 2007 to
obtain data from parents of children with cancer. This chapter provides the demographic,
descriptive, and substantive results of these interviews.

Sample Characteristics

Fifteen parents were interviewed for this study. Three of the participants were
interviewed twice in order to clarify and compare their responses, as is done with
theoretical sampling. Only one of the participants initiated contact with the researcher,
having read the flyer in the reception area. The other 14 parents were identified by clinic
staff as having a child in the maintenance phase of treatment and, after I approached them
and they heard the purpose of the research, they agreed to participate. All interviews were
held in the clinic either in a private consultation room or in the treatment room. The
children were, for the most part, not in the room when the interview was conducted. On
two occasions, the child was with the parent due to the child's age (under 4 years old) and

55

not having another caregiver present to stay with the child. The interviews lasted from 30 to 90 minutes. On several occasions, the parents chose to extend the interview to continue the opportunity to discuss their feelings related to going through their experience.

Sample Demographics

Twelve of the participants were mothers and the other three were fathers. Although an attempt was made to have an equal number of mothers and fathers, the majority of participants were mothers. This was largely due to the fact that the child's mother generally came to the clinic without the child's father. The children of these parents ranged from 2 to 18 years old. Ten children were diagnosed with acute lymphocytic leukemia, three with Ewing's sarcoma, and two with acute myelocytic leukemia. The time since diagnosis ranged from 5 to 22 months. All children were in the maintenance phase of treatment. The education level of the parents included high school (7), associate's degree (2), college (4), and graduate school (2). The occupations were diverse as well. Three of the mothers were homemakers, three worked part-time, and the other six worked full-time in professions from factory worker to banking manager. Two fathers worked full-time, and one had quit his job and worked from home to be able to be with his son in the hospital.

In addition to the diagnosis of cancer, the parents identified a number of other stressors currently affecting them and their families. Nine parents cited financial stress and seven acknowledged work stressors. Balancing the needs of their other children, spouses working out of town or being a single parent, having no family in town, dealing

with the educational and insurance needs of their ill child, and caring for elderly parents were also noted as concurrent stressors. Sample demographics data are listed in Table 1.

Participant Descriptions

A description of each parent/child dyad is described, giving pseudonyms for each participant and child. In this way, the reader can gain a more personal understanding of the families in involved.

Participant 1

"Becky" is a 34-year-old White mother of five children. She is extremely social and outgoing, has a bubbly personality, and talks with every staff member and family member in the clinic. Her fourth child, "Noah," is a 4-year-old boy who was diagnosed with acute lymphocytic leukemia (ALL) about two years ago. Becky is a born-again Christian and stay-at-home mother who home schools all five of her children. She is often seen in the clinic with most of her children with her. Her energy is amazingly high and she always seems upbeat and positive. Her husband travels a great deal with his work, which requires her to manage the children, house, schooling, and Noah's treatment on her own. She has no immediate family in the area but has a strong, supportive church community in which she is very involved.

Participant 2

"Audrey" is a 29-year-old African American mother of one child. Her son "Derek" was diagnosed with ALL a little over 2 years ago. She and her husband have graduate degrees and work full time in administrative/managerial positions. She describes herself as a realist and an even-tempered type of person. She and her husband had been

Table 1. Sample Demographics

Par #	Mom Dad	Age (yrs.)	Race	Age of child (yrs.)	Date of diagnosis	Date of interview	Occupation	Educational level	Other stressors
1	Mom	34	White	4	11/05	11/06	Homemaker	B.S.	$, husband travels, no family near, 4 other children, home schools
2	Mom	29	African American	4	12/05	1/07	Manager	M.S.	work, stepson
3	Mom	25	African American	5	1/06	1/07	Bank teller	H.S.	none
4	Dad	45	Korean	17	7/05	2/07	Store owner	B.S.	work, no family near, educational
5	Mom	42	White	4	12/05	2/07	Homemaker	2 yrs. College	11 other children, 1 w/ cystic fibrosis, home schools
6	Mom	34	White	14	9/06	3/07	School nurse	A.D.	divorced, $, other children, educational
7	Dad	37	White	5	8/06	3/07	Contractor	H.S.	$, occupational, noncustodial parent, lives in Florida.
8	Dad	42	White	15	11/06	4/07	Manager	M.S.	family, in-laws moved in
9	Mom	29	African American	10	12/06	4/07	Factory work	H.S.	$, divorced, shift-worker
10	Mom	39	White	18	11/06	7/07	School bus driver	H.S.	$, marital stress
11	Mom	26	White	2	1/07	9/07	Records specialist	H.S.	$, occupational, single-parent
12	Mom	26	African American	8	11/05	9/07	Nurse's aide	H.S.	$, 3-month-old baby
13	Mom	43	White	16	1/07	9/07	Homemaker	H.S.	family
14	Mom	44	White	10	3/07	11/07	School secretary	B.S.	$, no family near, work, teenage daughter
15	Mom	47	White	12	1/07	11/07	School nurse	B.S.	None

involved with their church prior to their son's diagnosis, but she states that going through this experience has increased the significance of the church and their faith in all of their lives. Audrey does not have family nearby and has only one other couple as close friends in this area. The biggest "surprise" that has come of this experience for her was that both her husband's company and her company have rallied behind them and offered a lot of flexibility and support throughout the process.

Participant 3

"Gerry" is a 25-year-old African American mother with one son. "Marcel" is a 5-year-old boy with ALL, diagnosed just over 1 year ago. She has a high school degree and works in banking. She has a very close extended family that all live within about a 15-mile radius of her. She has daily contact with her family and is very involved with her Baptist church community. Gerry reported that her husband has had a harder time dealing with this situation and that she has leaned heavily on her father for support. She stated that she tends to be an optimistic sort of person who puts a lot of trust in God to get her through difficult times.

Participant 4

"Jung" is a 45-year-old Korean father of two daughters. His youngest daughter "Sara," age 17 years old, was diagnosed with ALL over 2½ years ago. She has had several significant complications related to her treatment and, as a result, has some physical limitations (abnormal gait). Jung and his family moved to the United States from Korea about 6 years ago. In Korea, he had worked as an engineer but, since moving to the United States, has worked in more 'blue collar" jobs. Eight months ago, he went into

business for himself in order to be available to bring his daughter to the clinic for treatment. His older daughter had recently left for college, but she comes home frequently to help out. His wife does not speak English and does not drive, leaving the majority of interactions with the medical community up to Jung. There are a significant number of outside stressors, such as financial, occupational, and educational concerns. His family is involved with a Korean Catholic church, which has been very supportive.

Participant 5

"Sarah" is a 42-year-old White mother with seven biological children and five adopted children. Their ages range from 8 months to 21 years old. Three of her children have Down syndrome and one has cystic fibrosis. "Rose" is her 3½-year-old daughter with Down syndrome who was diagnosed with acute myelocytic leukemia 2 years ago. Rose is very small for her age and developmentally delayed, even for a child with Down syndrome. Sarah home schools all of her children (the two oldest are in college) and has had 2 years of college. Her strong religious convictions have "led" her to adopt children with medical complications, but she feels that the diagnosis of cancer was something for which she was not prepared. Still, her religious beliefs in an afterlife provide comfort for her when she thinks about the possible negative outcomes for Rose.

Participant 6

"Katie" is a 34-year-old White mother of five children. Her 14-year-old son, "Sam," was diagnosed with Ewing's sarcoma a little over 1 year ago. She works part-time as a school nurse and lives with a large extended family in a small seaside community. Other stressors included planning for her oldest daughter's wedding, which

was to occur in 8 months, and dealing with financial strains associated with decreasing her hours at work to care for Sam. Katie describes herself as a spiritual person, but not necessarily very religious. She was one of the parents to describe the epiphenomenon (a term explained in more detail later in this chapter).

Participant 7

"Matt" is a 37-year-old White father who is the noncustodial parent of 5-year-old "Ben." Ben was diagnosed with ALL 1½ years ago. Matt lives in Florida but drives back at least once a month to be with Ben for clinic appointments or hospitalizations. He gave up his previous job and now works as an independent contractor to give him a more flexible schedule to be with his son. He has three older children. He and Ben's mother had been separated for 2 years before Ben was diagnosed. Matt was very emotional during the interview and stated that he did not get the opportunity to talk about his feelings related to this experience very often. In addition to the stress of being out of town, he had financial stressors and his own father was also very ill with cancer.

Participant 8

"Cabell" is a 42-year-old White father of 15-year-old "Chad," who was diagnosed with ALL just 5 months ago. Chad is Cabell's only child, and Cabell describes their relationship as extremely close. Cabell has a graduate degree and holds a rather influential position in management in a local company. He has a commanding presence and is used to being in control. He is with Chad at every one of Chad's clinic appointments and demands to have every lab result copied and given to him to keep in his file. He is constantly questioning the staff, although he has nothing but high praise for

them. He initially said that he did not want to participate in the study, because he did not think that any benefits had come from his experience. His son convinced him to talk with me, because Chad had seen some very positive changes in his father since his diagnosis, so Cabell agreed. He ended up becoming emotional on a couple of occasions during the interview as he came to realize some of the benefits that had occurred in addition to some fears and concerns he has a hard time sharing with others.

Participant 9

"Bernice" is a 29-year-old African American mother of two boys. She is divorced and relies on her elderly mother for help with the boys. Her 10-year-old son "Marcus" was diagnosed with acute myelocytic leukemia 5 months ago. She lives 2 hours from the clinic and is dependent on Medicaid vans for transportation to and from the hospital. She works various shifts in a local meat-processing factory, where she earns minimum wages. Her son was diagnosed after experiencing a frightening and lengthy nosebleed that started while Bernice was at work, which her mother and 8-year-old son were left to manage. Bernice's ability to process information was slow, and she did not seem to understand the more conceptual questions asked of her, so the interview focused mainly on types of benefits she identified. She answered these questions appropriately.

Participant 10

"Bridgette" is a 39-year-old White single mother of three children. Her oldest son "Brad" was diagnosed with ALL just over 1 year ago. She describes herself as a born-again Christian and had total faith that her son would be okay. She is a school bus driver and stated that her financial concerns and dealing with her ex-husband worried her more

than her son's diagnosis. Bridgett gave a very detailed description of the epiphenomenon (a term explained in more detail later in this chapter), although it was related to her mother's death a few years earlier. She stated that it was that experience that allowed her to cope with any fears about her son's diagnosis and treatment.

Participant 11

"Emily" is a 26-year-old White single mother of "Seth," her 2-year-old son who was diagnosed with ALL 9 months earlier. She works in the police department and had lived with her parents until just recently. She related many other stressors in her life including financial, occupational, and emotional. She said that she was not a particularly religious person and was surprised at how well she was handling the whole experience of her son's cancer. Emily's account was unusual in that she said she was never afraid, that she just always knew that Seth would do fine with the treatment. She receives a lot of support from her parents, and she said that her mother probably does all the worrying for the both of them.

Participant 12

"Tanya" is a 26-year-old African American mother of two boys. Her oldest son "Darnell" is 8 years old and was diagnosed with ALL almost 2 years ago. She worked as a certified nursing assistant until Darnell's diagnosis. She also has a 3-month-old infant. Tanya is a quiet woman and deeply religious, saying that she had to hand everything over to God. She described the epiphenomenon and said that, since turning that corner, her fear has been much less.

Participant 13

"Elizabeth" is a 43-year-old White mother of three children. Her oldest son "Mark" is 16 years old and was diagnosed with Ewing's sarcoma 9 months earlier. He required extensive surgery to his leg and had part of his bone replaced, due to the extent of the tumor. Elizabeth has a very positive attitude, upbeat and future oriented. She reported that she was more fearful prior to the diagnosis, but had faith in the hospital staff and the treatment from early on.

Participant 14

"Teresa" is a 44-year-old White mother of two children. Her youngest son, "Daniel," was diagnosed with ALL 7 months ago. She works as a secretary in the public school system. She had lived in a northern state most of her life and moved south with her husband and two children just over 6 years ago. She has no immediate family in the area and related this as one of the stressors, which made this a more difficult experience. Additionally, her husband had started a new job just four days before Daniel's diagnosis, so insurance concerns were there as well. Teresa described the epiphenomenon and turning a corner as leading to her being able to cope with the fear.

Participant 15

"Angie" is a 47-year-old White mother of two children. Her youngest child, "Stacy," was diagnosed with Ewing's sarcoma 9 months earlier. Angie works as a school nurse and reported no other concurrent stressors. She said the treatment was hard in the beginning because Stacy is an avid athlete and it was not known how severely her activities would be curtailed following surgery. The chemo shrunk the tumor enough to

limit the extensive removal of bone, and Stacy has returned to competitive horseback riding. Angie described an epiphenomenon in great detail, although it was related to an experience that happened with her son almost dying in a neonatal intensive care unit over 14 years ago. As a result of that experience, Angie was able to build on those feelings and came to turn a corner rather quickly in this experience with her daughter. She relates that experience as making her a believer, and she has relied heavily on her faith ever since then.

Model Development

One way to provide an overall picture of how the model in this study was developed is to tell a story based on the accounts the parents gave of their experiences of their child's diagnosis and treatment. This story is intended to capture the essence of the experience and to identify the process and concepts that emerged during the course of the study. Although not all parents identified every concept described in this composite story, all of the concepts were identified by several of the parents, and the overall sequence was the same for all parents.

Composite Narrative

Our son had been sick off and on for several weeks with what we thought was the flu. He was running a fever and just didn't have any energy. We had taken him to the doctor, who pretty much said the same thing and, so, we just had him stay home from school and rest. But he just wouldn't get any better and that's when I sort of started worrying, like, "What is going on here? Is it something worse?" And then you kind of just get so worried that you just don't know, and you think the doctor doesn't know and it

just gets so scary. So we took him to the doctor's again and she said she wanted to do some blood work. The waiting was so bad, and then when she finally called and said, "I want you to go to MCV [Medical College of Virginia hospital] and have Jason looked at by the doctors there," well, that's when I really panicked. She said his white blood cell count was really high and the he might have leukemia. And, my gosh, when you hear that word about your own child, it's just too much. I don't even remember driving down there. My mind was just racing, thinking, "What does this mean? Is he going to die?" And then when they confirmed it, it was like a huge wave was just swallowing me up. I felt like I couldn't breathe, but like I couldn't fall apart because I still had to be there for Jason. I mean, you do just want to fall to the floor sobbing but, because you're the parent, you just can't do that.

The first few days were just a blur. Everybody was so nice; we got so much support. The staff and doctors were reassuring, and my family came down. My boss just told me to take off as much time as I needed. Our pastor came by and prayed with us, and all of that helped so much, but it still felt so overwhelming. I remember sitting there in the hospital room, looking at Jason asleep in the bed and I just started sobbing uncontrollably. It felt like I was crying for hours and I finally said to myself, "God, if I don't stop crying right now, I'm going to go crazy and I will never stop." And then all of a sudden, I stopped crying. I felt this sense of peace come over me, and I just knew after that that I could handle whatever came my way. I don't know what it was, if it was some kind of intervention from God, or what, but I just felt completely different and, after that, I just felt, well, whatever happens, I'm not alone and I can do this. I'm not a real religious

person, but I always did believe in a Higher Power or something, but this experience gave me faith that I can handle this. I've heard other people say that you just have to give it over to God, but I never really knew what that was like, but there was this sense that there is so much that is out of my control and I just had to put it in God's hands. And I did, and I felt better.

In addition to that experience, the other thing that helped a lot was knowing that Jason was on a protocol and the doctors explained everything to me, and it really helped to know what to expect. And then, when Jason started to respond to the treatment and I saw him getting better, then I felt even better. It just felt like we were going to move through this and he is going to get better.

So after the first week or so, once he was on a protocol and he was getting better, I didn't feel so overwhelmed. I felt like I, we, could cope with all of this. So, we got into a routine and started planning how things would work between home and the hospital. You just kind of draw on your resources, you find this inner strength and you just do it. I think that having faith in a good outcome is really important and just taking things day-by-day and keeping things in perspective. All of those things help you get through this.

And about benefits, I think there have been so many. I mean, sometimes my friends or family think I'm crazy because I tell them that we are so blessed. They say, "Your son has cancer, how can you think you're blessed?" But there have just been so many good things that have come out of this. That first month, I swear we must have gotten 80 dinners from friends and family. And people who I'm not even really close to. I had no idea that they cared, but everybody would bring over food or toys and tell me that

they would be there for us. And my family, we've always been pretty close, but you know, they don't live around here, so we kind of drifted apart. But now, my mom and I talk on the phone everyday, and she comes down whenever I need her. I feel so much closer to her, to both of my parents. And I definitely feel as if I've gotten closer to God. I feel a deeper faith and just feel like I'm not alone in this, that there's a Higher Power that is helping out somehow.

I think also that I'm definitely a stronger person because of this. I mean, before, I hardly ever questioned someone, especially someone in authority. I just kind of accepted what the other person said and didn't say anything if I disagreed. But now, if I don't understand something or I disagree with something, even if it's the doctor's saying something, I'll say, "Hey, wait a minute. What's going on here? Is this what's best for me and Jason at this time?" I would have never done that before.

I'm also much more patient and understanding. Before, some of the littlest things would bother me, but now, it's like, oh no, that's not a big deal anymore. It's like you don't sweat the small stuff because you know that you've been through one of the hardest things a parent can go through, so there's not a lot more that can scare you. I mean, the fear of Jason relapsing is still there, but the outside things, they're just not something you worry about as much. But your priorities are just so different. You know what's really important now and you do that stuff and let all the other stuff go. You don't put it off, like spending more time with Jason or doing stuff with him and the family that he's wanted to do for a long time, but like you never got around to it. But now it's like, hey— you never know what will happen tomorrow so let's do it today. It's things like that that

are more important. And also my husband and I, we've actually gotten closer, and now we always remember to kiss each other hello or good-bye because you know that's what is most important. The here and now.

Description of the Theoretical Model

The process of benefit finding emerged through the parents' narratives. Through analysis, it became clear that the Basic Psychosocial Problem, or the issue that initiated the process, was that of being overwhelmed with fear. As evident in the composite story, the parents began to feel fearful when their child developed unusual symptoms or symptoms that initially had no explanation. The parents expressed being overwhelmed by fears that fell into three categories: (1) fear of the unknown, (2) fear of their child dying, and (3) fear of the parent losing all control. The parents then identified several factors, or intervening conditions, which helped move them from feeling overwhelmed to feeling that they could manage the fear. These intervening conditions are getting information, getting support, having trust/faith, seeing their child improve, and the passage of time. In addition, many parents identified a specific event, an epiphenomenon that created a turning point for them. This event, along with the intervening conditions, moved the parent from being overwhelmed to managing and transforming the fear, which is the Basic Psychosocial Process. The parents identified the following strategies that helped them manage the fear: being in the present, being strong, maintaining hope/faith, and making meaning out of the event, of which benefit finding is the major component. This entire process occurs within the context of being a parent, because this awareness colors the entire experience. This theoretical model is depicted in Figure 2 and Table 2.

Context:
Being a Parent

Intervening Conditions
- Getting Information
- Getting Support
- Having Trust/Faith
- Seeing Child Improve
- Passage of Time

Basic Psychosocial Problem:
Being Overwhelmed with Fear
- Fear of the Unknown
- Fear of Child Dying
- Fear of Losing Control

Turning a Corner
- Epiphenomenon

Basic Psychosocial Process:
Transforming the Fear
- Being in the Present
- Being Strong
- Maintaining Hope/Faith
- Making Meaning

Finding Benefits
- Growth in Character
- Strengthening Relationships
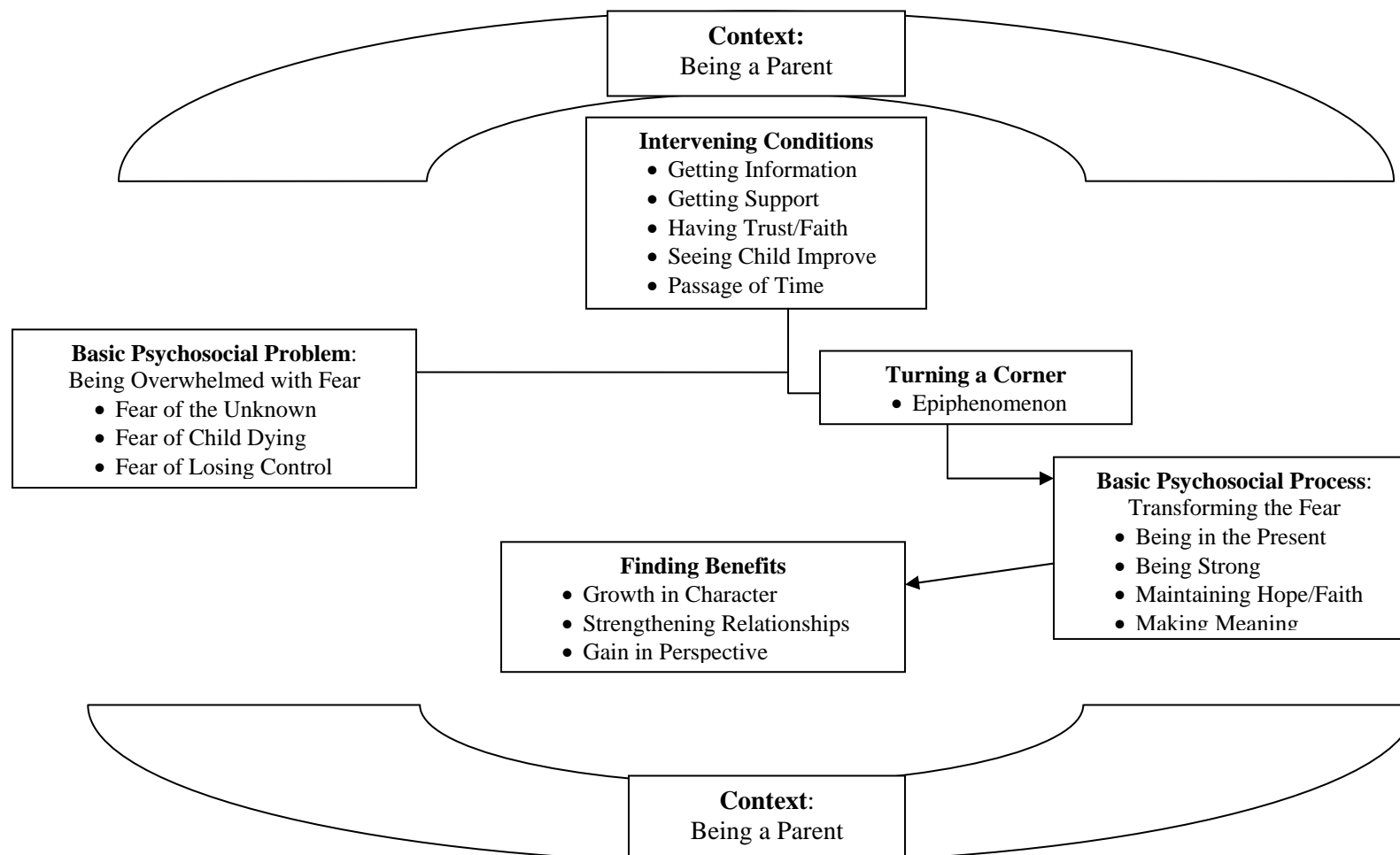- Gain in Perspective

Context:
Being a Parent

Figure 2. Theoretical Model of Benefit Finding in Parents of Children with Cancer

Table 2. Outline of the Theoretical Model of Benefit Finding

Categories	Properties	Subproperties
Basic Psychosocial Problem: Being Overwhelmed with Fear	• Fear of the Unknown • Fear of Child Dying • Fear of Losing Control	
Intervening Conditions	• Getting Information • Getting Support • Having Trust/Faith • Seeing Child Improve • Passage of Time ———— • Turning a Corner	• Family, community, staff • Self, child, staff/treatment/ Higher Power ———— • Ephiphenomenon
Basic Psychosocial Process: Transforming the Fear	• Being in the Present • Being Strong • Maintaining Hope/Faith • Making Meaning ———— • Finding Benefits	———— • *Growth in Character:* strength, patience, growth, altruism • *Strengthening Relationships:* family, friends, Higher Power • *Gain in Perspective:* reprioritizing goals, re-evaluating lifestyle

Context: Being a Parent

Contexts provide important meanings that influence how an experience is viewed and the value of theoretical relationships that emerge (Chinn & Kramer, 1999). In the present study, being a parent is the context that influences how each aspect of the process of benefit finding is experienced.

Being a parent is a unique and universal experience, both personal and public. It encompasses a sense of deep responsibility for someone other than oneself, coupled with profound feelings of vulnerability. Parents' responsibility entails an obligation to protect

and nourish their child, to shield their child from painful experiences and to be in charge

of their child's well-being. Simultaneously, a sense of vulnerability occurs, stemming

from the parents' deep love of their child with the knowledge that they cannot control all

the forces that will impact them. An altruistic aspect exists in that parents put their child

first and give unconditionally, without the expectation of a return. This sense of

connection is a deep and powerful bond that creates a different reality for parents

regarding the meaning and purpose of their own life. They experience an increased

awareness of both the simple beauties and complex dangers life presents. One mother jn

the current study expressed it this way:

> Well, when the doctor said that she had it and my mother was there with me, and
> there's cancer all within my family, and it's supposed to be me, not her, and I
> would give anything if it was me instead of her. For me it would be much easier if
> it was me…it shouldn't be my child it should be me. (Angie)

Another parent, a father, said, "I would much rather this happen to me. You don't even

think about that" (Cabell). When reflecting on the sense of responsibility as a parent, this

same father also stated:

> Right, right. There's a cause and it's biological and we can't find it but I want to
> get to the root cause and I want to fix it. And I also know that my wife and I are
> the only two people that are consistently looking out for him every day; whether
> we're here at the clinic or in the hospital there's help and the focus of professional
> individuals for a period of time. But that ends as soon as their shift ends, so you
> know what I mean, so we're the ones. This is our time. (Cabell)

Many parents expressed a sense of guilt that also influenced the process, as

illustrated in the following statements:

> I think if it was myself that was diagnosed, I'd say, "OK, I've got to fight this;
> everything's got to be normal for the kids." When it's your child, you think, "Oh
> my gosh, what have I done? I should have protected [her], I should have…" You
> start looking first at, OK what causes this, like, where did I bring them, what did I

expose them to? What could I have possible done that would have prevented this? I think if it was yourself [with the diagnosis of cancer], you just think, "OK we're just going to get through this. We're going to take chemo…" You wouldn't ever think [of placing guilt on your own mother], "Mom, what did you do to me?" You wouldn't ever place that burden on anyone else. (Teresa)

[Crying:] Sometimes I just wonder why it had to happen or was it anything I caused, you know… (Bernice)

I think the hardest part was the guilt because he had been telling me for so long about his arm. (Katie)

Oh, my goodness, in the beginning, really. I would rather for it to be me; you know, than my child. It was a hard pill to swallow. I went through a lot of stuff in the beginning, the whole, "Why?" Blaming yourself in the beginning, you know, like, scared of the unknown…. (Tanya)

Thus, the experience of benefit finding is influenced by the vulnerability, the deep sense of responsibility and feelings of guilt and helplessness that come with the role of being a parent. Many parents say that their worst fear is having something bad happen to their child; the diagnosis of cancer is, for many, their worst fear being realized. The main issue, then, for a parent of a child with cancer is being overwhelmed by fear.

The Basic Psychosocial Problem

In describing their experience, most parents expressed the common feeling of overwhelming fear. They identified the fearful feelings as being present throughout the experience, although the intensity changed as they used various coping techniques. Thus, the basic psychosocial problem, the issue that spurred the process, is being overwhelmed by fear. Parents expressed three major types of fear: (1) fear of the unknown, (2) fear of their child dying, and (3) fear of losing their mind or losing control.

In the beginning of their child's cancer diagnosis, parents described the intensity of their fear as being overwhelming, a feeling reflected in the definition "to cover over

completely, as by a great wave; to bury underneath; to overpower, oppress" (Webster's

New International Dictionary of the English Language, 1934, p. 1743). The experience of

being overwhelmed by fear has been described at length in nursing as well as psycho-

oncology literature and is one of the defining characteristics of a crisis. According to

Evans and Madsen (2005), "The hospitalization of a child is one of the most traumatic

episodes of parenthood. The fear, frustration, anger, and loss of control can be

overwhelming to the parents of the critically ill child" (p. 188). In a study of childhood

cancer, McGrath (2002) found:

> The parents' insights provided a clear indication that the initial stage of treatment
> is highly stressful and parents may be overwhelmed by the experience. The
> situational stress translated into three potentially overwhelming emotional states:
> the stress of uncertainty, the shock of diagnosis, and a feeling of being trapped in
> an unpleasant emotional roller-coaster ride. (p. 988)

Findings from a study by Kupst and Bingen (2006) provide further support for the

experience of being overwhelmed: "The diagnosis of pediatric cancer is one of the most

stressful situations a child and family must face. It presents an overwhelming series of

stressors, not the least of which is the possibility of the child's death" (p. 35).

In terms of intensity, the parents who expressed fear all stated that it was worse in

the beginning. Examples of feeling overwhelmed include a mother who felt as if she had

to shut out the world just to get through the day. "The first month I was so overwhelmed I

didn't want to talk with anyone else, I fell apart with fear and exhaustion" (Sarah). Other

parents provided the following descriptions of the intensity:

> I mean in September every day was horrible for me, I just would wake up and it
> was the first thing I thought: Sam had cancer and it was the last thing I would
> think about before going to sleep. I would go into Wal-Mart and everyday life
> was happening and I would look around at people and think, "What is wrong with

you people? My kid has cancer. Why are you people happy? How can you be buying a balloon?" Looking back, it seems ridiculous, but it was the most crushing, I was being buried alive. (Katie)

At first you don't want to believe that they're sick. Then, living by myself it seems that all the TV shows would have kids with cancer and I would just sit there and cry by myself because there's nothing you can do…. I feel overwhelmed so often. I wake up at 3:00 in the morning and I feel like, "How am I going to get through this…the rise and fall of this?" That's what will send you to the other side of insanity. (Matt)

My husband and me, we were really stressed to the point that I couldn't even function. I mean I was really, really, stressed to the point that I stepped out in front of a car because I was so stressed. (Angie)

Well, for me, from the moment the doctor said, "You need to go to the pediatric emergency room," that's when it started. I thought, "Oh my God, what's going on?" And I think I reached the parking lot before I started breathing. (Teresa)

Research supports parents' initial experience as being overwhelming. Wong and Chan (2006) found parents describing their reactions to their children's diagnosis as "shock, denial, worry and…that their [parents'] brain was blank at that moment of knowing the diagnosis and they lost the capacity to feel" (p. 713). In another qualitative study conducted by Patterson, Holm, and Gurney (2004) and involving 45 parents of children who had been off treatment for cancer for at least 1 year, the parents described the initial experience as "feeling numb, devastated and overwhelmed and having a sense of helplessness and loss of control" (p. 396).

Fear of the Unknown

In the present study, parents who expressed a fear of the unknown generally referred to their fear as arising in the beginning, before a diagnosis was given to their child, as well as fear of not knowing how the treatments would affect their child. This

sense of uncertainty creates great anxiety in the parent, contributing to the feeling of

being overwhelmed, as illustrated in the following statements:

> Not knowing for me is the worst and I worried so much but once I knew what it
> was I was like, ok, now I know, what do we do? (Audrey)

> It's hard for parents and the initial thing is devastating for you but then once you
> grasp it and what it means and what you have to do for your child to have a
> chance to fight this, then you just do what you have to do. (Becky)

> I worry the leukemia need[s] long-term treatment and some strong medicine.
> (Jung)

> In the beginning it was horrible; I mean the stress was unbearable, really horrible.
> The worst part….I don't know. He had had arm pain for two years but it was
> never diagnosed (several doctors looked at it). So it was nice to finally get the
> diagnosis but then the diagnosis was horrible. (Katie)

> …and you realize how grateful you are for knowing, even if your child has
> cancer, which scares everybody to death, but at least you know what it is....
> (Audrey)

Some of the parents said that the fear of not knowing was the greatest fear they

experienced. These parents felt more in control after they knew what was wrong with

their child and could develop a plan to deal with the illness. For others, the diagnosis of

cancer immediately implied the potentiality of their child's death—a fear so great that the

parents felt they could not cope.

Fear of Child Dying and Fear of Losing Control

The fear of their child dying was closely related to the parents' fear of losing all

control. Many parents could not even say the words "death" or "dying" out loud. They

made reference to, but could not say, the words, as illustrated in the following statements:

> …they came in and told me what he had and they wanted to take bone marrow
> and they sedated him. And that's the first time I've ever seen one of my children
> sedated like that, and he just laid there and it didn't look good to me to see your

child just laying there and the thought came across my mind, "You know, he has cancer," and seeing him laying on the bed like that, it was too much for me. And I have never been that afraid. (Tanya)

When she was first diagnosed, I was scared and I didn't think I could do this, I got overwhelmed. (Sarah)

And it just hit me one day, "OK, I can't do this, this is killing me." (Katie)

I would just sit there and cry by myself because there's nothing you can do. (Matt)

…I could hardly drive after seeing those x-rays. I was in a panic…. (Cabell)

…and then you go into the hospital and it's like, there they are, they're in pain and it's like you can't do anything and they look at you like, "Mom, why are you letting them do this to me?" And then it just goes downhill from there…. [The worst fear] was the fear of losing him. That was the full point and I was going to do anything in my power.... (Teresa)

The basic psychosocial problem, being overwhelmed with fear, eventually led to a turning point for parents. For many, a turning point came when they no longer felt overwhelmed, but instead felt as if they knew what to do and that they could do what it takes to cope with the diagnosis of cancer in their child. They identified several external factors that helped get them to this point, and many identified an actual moment of personal transformation that created an internal shift from panic to peace, allowing them to feel more in control and able to move forward. The external factors are identified as intervening conditions, and the internal shift is called an "epiphenomenon." The epiphenomenon was one of the most interesting aspects of the benefit-finding process that emerged in the course of this study.

Intervening Conditions

The factors that parents said that helped them to get past feeling overwhelmed were getting information, getting support, having trust/faith, seeing their child improve, and the passage of time.

Getting Information

Getting information was important to all the parents in helping them move past the feeling of being overwhelmed. Information came from a variety of areas: the nursing and medical staff, the Internet, and other parents of children with cancer. Getting information helped decrease the parents' fear of not knowing and, for many, it decreased the fear of their child dying as they learned about the potential success of treatment. Seeking and obtaining information about the disease and treatment has been shown to be a common and useful coping strategy used by parents after diagnosis of cancer or other chronic illness in their child (Pyke-Grimm, Degner, Small, & Mueller, 1999). Parents in the current study provided the following comments on obtaining information about their child's diagnosis:

> You realize how grateful you are for knowing, even though your child has cancer, which scares everybody to death, but at least you know what it is and you can get started on a path…. (Audrey)

> It was helpful to read the book they give you, and I kept track of everything. (Bridgette)

> Oh, yes, feeling like you can never learn enough…. I did a whole lot of searches on the Internet…and also from other parents. We've connected with another child here…they have the same diagnosis…and we share information about education, the protocol, and that's helped a lot. Not only the parents, but [it helps] the children, too, to see each other. (Teresa)

I was not as overwhelmed with what I needed to do because this hospital, this clinic is really good about, you know, everything [you need to know] about setting up homebound studies, to whatever. They take all of that load off of you. (Elizabeth)

The importance of getting information has long been acknowledged in the health care field. Nurses incorporate educational strategies to assist patients and their families in coping with a diagnosis. Getting informed helps one gain control over a situation in which he or she may have felt or feels helpless, thus helping to create the sense that one has the ability to move forward (Hamburg & Adams, 1967; Lewandowski & Jones, 1988; Meissner, Anderson, & Odenkirchen, 1990; Tringali, 1986).

Getting Support

Every parent in the present study related how important it was to get support in helping them manage. Support came from family members, other parents of children with cancer, friends, the staff at the hospital and the clinic, church and community organizations, and employers. The parents spoke of being surprised at the outpouring of care and of the various ways people reached out. Some parents also related that support came from unexpected sources, such as a stranger in a store or, for one mother, the secretary in the dean's office at the university her daughter (without cancer) was attending. The following statements illustrate the parents' experience with receiving support:

I started crying in the beginning and I think it would be harder without family, I really don't know how I could have done it. (Gerry)

I had never been in a position where I needed it [help], but this was a different situation and people said, "Let me help," and I needed it then…just knowing they were there made a difference. (Sarah)

I think the most overwhelming part is finding out how many friends you really have in your community. That was just unbelievable, overwhelming. We had 80 meals, and that was just at one of the schools. Then came the churches. That was just overwhelming, that's the part that made me cry the hardest; realizing what you're blessed with. (Elizabeth)

…and then 2 days into it all, these people were here. Look at all this food, everyday. It was overwhelming…I mean the visits, the things they're making him, the videos, all kinds of special things. (Cabell)

The people in here are great. Everybody's just awesome. From the first day he was in the hospital, you just get great support. (Bridgette)

From the minute we got here, I feel overwhelmed [in a positive sense] by the way people treat us all. Not just [my child]. Cathy [a nurse] is amazing; she's our link to everything and everybody. She has made this bearable. (Katie)

Dr. M would call and talk with me. She is so good, I felt she really cared and that made it easier for me that she just really cares. (Sarah)

The nurses are just so genuine. (Gerry)

My church fellows want to give me and my family [help]…it was great help. (Jung)

People at church are really supportive and do a lot of praying. (Gerry)

People at work donated leave time to me, it was really nice. (Bernice)

Work was very nice to me; real good. I tell them when I need off and they just say fine. (Bridgette)

Research findings demonstrate that nurses and other health care providers are major providers of support to parents of children with cancer (Adams & Deveau, 1988) and that their support is particularly helpful to parents in the initial weeks following their child's diagnosis (McGrath, Paton, & Huff, 2005). McGrath (2002) identified four factors that parents stated helped to create a supportive environment: (1) honest and sensitive information about their child's diagnosis and treatment; (2) information on the practical

issues such as expected side effects, time lines, and test results; (3) the staff's support in

the form of making a space in which the parents felt comfortable sharing their feelings;

and (4) the staff affirming their views. According to McGrath (2002), this support helped

the parents trust the staff, which was another important factor in helping the parents move

from being overwhelmed to turning a corner.

Having Trust/Faith

For parents in the present study, having trust or faith not only related to God or a

Higher Power but also involved the parents having faith in themselves, their child, the

staff, and the treatment. Many of the parents stated that they relied on their religious or

spiritual beliefs heavily in the first few days or weeks following their child's diagnosis.

The following comments demonstrate the parents' reliance on trust or faith:

> I have a belief that no matter what happens, that God is in control…I mean I
> wouldn't say it's been easy 100% of the time, but it's been easier. (Angie)

> I think I would be void of joy [if I didn't have my faith]; it would be very
> traumatic for me, I wouldn't, I don't know how I would handle it, I wouldn't have
> strength, I would just be…I think I would just be in despair, there would be no
> hope. (Becky)

> I went through a lot of stuff in the beginning…you know, like scared of the
> unknown, but prayer is the answer to everything for me. It answered everything at
> that moment and I haven't had any feeling like that [being overwhelmed] after
> that, cause it's just a feeling of knowing that everything's going to be just fine.
> (Tanya)

> I was getting ready to falter…I knew that there were so many people praying and
> that all the powerful positive stuff coming our way would help us stay up and
> make it another day. (Elizabeth)

> Absolutely, that's what got me through the first night, was just praying to God to
> keep me together, don't let me fall apart, let me stay together for [my child], and
> that's how we got through. (Teresa)

But I know that we've got God, God is here and He is with us and no matter what happens, we can get through this because we have God with us. (Sarah)

I believe and wife believe God gave us potential to recover from the difficulties. (Jung)

Some parents described having faith in their child's ability to fight the cancer and come through the experience with little consequence. As one participant, noted, "I don't know why I had that faith, but I just know he's going to be OK. There have been times that haven't been so good, but I've just known that, in general, he's going to be all right. And I know that's helped a lot, too" (Emily).

In addition, many of the parents expressed their faith and trust in the clinic staff, as illustrated in the following statements:

…it felt like they [the clinic staff] really knew what they were doing…so I just kind of felt we were going to get through it. (Elizabeth)

You just have to tell yourself that they're [clinic staff] doing the good thing; this will help him. To do it, it falls on faith; you have to believe they're doing it because it's the right thing. (Matt)

Walker, Wells, Heiney, Hymovich, and Weekes (1993) addressed this aspect of the psychosocial care needs of parents of children with cancer in stating that "in periods of anxiety and confusion, parents need to trust that their child is receiving the best possible care" (p. 418). The parents' faith in the treatment and the staff is further strengthened when they see that their child is improving.

Seeing Child Improve

All of the parents in the current study talked about how important it was to see their child get better. They related their own emotional functioning on the condition of their child; knowing their child was responding to the treatment in a positive way helped

decrease the parents' anxiety and increase their sense of being able to get through their stressful experience. The following statements highlight the importance of the parents seeing their child improve:

…and then Daniel started to get better…. (Teresa)

…'cause when you know he's doing well then we're all given a boost and it keeps you going. (Matt)

When he gets better, and you see signs of normalcy in him, then you feel better…I mean my anxiety started way before that. I was looking at Chad's [symptoms] and they weren't getting better and my anxiety was getting worse. When I see that he's on a protocol and I see that there's a good percentage of survival then, yeah, I'm getting better…if he's doing well, I'm doing well. (Cabell)

Although no studies were found that specifically correlated the child's improvement with parental psychological well-being, intuitively, this occurrence makes sense. The correlation is a universal aspect of being a parent.

Passage of Time

One of the inclusion criteria for the present study was that children were to be in the maintenance phase of treatment, thereby affording the parents the time to adjust to their child's diagnosis and treatment. The phrase "time heals all wounds" comes to mind when relating this aspect of the process to how parents arrive at a turning point. Previous studies of positive emotional adjustment in parents of a child with a life-threatening illness found strong correlations between coping and the passage of time (Fife et al., 1987; Kupst et al., 1995). In the present study, parents provided the following comments related to the positive effect of the passage of time since their child's initial diagnosis:

Probably by the time we started the actual chemo and we kind of got things into an actual routine, when things got settled and not so hectic, [we knew] what we

were dealing with and how this was going to work out with our real, everyday life. Then I could sit down or something and focus on, "OK, now how can we handle this?" (Katie)

Here we are five, six months into it and I'm still scared. But I don't think I'm as scared as I was the first two days. (Cabell)

The first month was the hardest...the first month, I was so overwhelmed...but right now, things are going along OK. (Sarah)

Steele (2005) reported similar sentiments from participants in a qualitative study of families who had a child with a terminal illness:

Strong emotions of fear, uncertainty, and grief were always present, but changed in intensity over time…. [F]ear and uncertainty were stronger at the beginning, when parents became aware that something was wrong….[A]s parents employed strategies to manage the cognitive and emotional work, the fear and uncertainty dwindled. (p. 38)

Turning a Corner

The experience of turning a corner happened for different parents at various times into the treatment. For some, it happened relatively quickly, within the first week or so after diagnosis. For others, it came later in the process, perhaps a month or so after. The combination of getting information, getting support, having trust or faith, seeing their child improve, and the passage of time brought them to the point of no longer feeling overwhelmed by the experience, but feeling a sense of control in their ability to handle this stressful situation. In addition to these five factors, several of the parents identified an actual episode or specific experience that further helped them cope more effectively.

Epiphenomenon

During the course of this study, several parents related a similar experience that is being termed as an "epiphenomenon." For this study, an epiphenomenon is defined as a

paradoxical event that occurs in the process of benefit finding that entails the parent,

when overwhelmed by fear, calling out for help and experiencing an intercession, perhaps

on a paraconscious level, that results in a transitive state—the fear is replaced with a

sense of peace. An epiphenomenon helps one appraise the situation with a more positive

outlook and gives one the feeling that he or she can cope with the situation. The

operational definition of the epiphenomenon is broken down and described in Table 3.

Table 3. Operational Definitions of "Epiphenomenon"

Term	Definition
Epiphenomenon	An attendant or secondary phenomenon appearing in connection with something else and thought to be caused by the latter.
Paraconscious	Accompanying, but independent of ordinary consciousness.
Transitive state	A passing between one condition and another.
Intercession	An intervention, an act of mediating.

Parents described the epiphenomenon in similar ways.

> When she was first diagnosed, it was almost like a denial, and then, when it hit me it was like it can't be happening to me and then it was like this fear and then you kind of turn it over to God and it was acceptance. (Angie)

> Well, the first day, wow, when they first told me that he had cancer, I think I prayed right then; it hit suddenly, although after that day, I mean I prayed on it and after that day, everything's been going well…I got a feeling of peace, and [I felt] everything was going to be OK. It helped me cope…no, I don't have too much fear anymore; turning that corner really helped. (Tanya)

The following description of the epiphenomenon experience did not happen in relation to this mother's coping with her child's cancer, but she so eloquently described this event that she experienced several years earlier that it is included it in this section. She said that, had she not experienced this with her mother, she was sure she would not have been able to deal with her son's illness with the strength and faith that she had. She had been extremely close with her mother and had cared for her while she slowly lost her to Alzheimer's disease. Following is her account of this epiphenomenon:

> ..that first Mother's Day was really hard and not long before that I had been saved and I had been going to church and hearing that you've got to just hand it over to God; you've just got to trust in God. Then that Mother's Day, I went to church and I just broke down and I cried and I ran out of church in the middle of service and I went home. I just sat and I cried and I cried and I cried, and I just said, "I can't do it anymore." And I just said, "Please just give me peace." And I felt this wave just rush over me. And it did. And that's why I believe in it and that's why I do [believe]. And if I just can't do it no more and I need peace? It happens. (Bridgette)

Another woman described the event in the following words:

> My mom used to have this old saying, "You just have to let go and let God; just turn it over and be finished." And it just hit me one day, "OK, I can't do this; this is killing me."… But one day I said, "God, I just can't do this anymore. You're going to have to just help me out." And, I just felt like, you know I didn't have an epiphany—no angels showed up. I just felt better. I just felt like, "OK, now I've got a little help." And since then, I've kind of just related it to myself inward and I feel that, as I look back at everything that has happened, I feel like we've been blessed in so many ways. (Katie)

All participants identified benefits they found within their experience, regardless of whether they experienced an epiphenomenon. There was an aspect of being able to let go of control, there was a trust or faith or a sense of peace that the participants who experienced the epiphenomenon had that the others did not.

The Basic Psychosocial Process: Transforming the Fear

The basic psychosocial process is the collection of management strategies or coping strategies in which parents engaged in order to transform their fear. In general, the parents acknowledged that fear was always present in lesser or greater degrees throughout the entire trajectory. The fear increased during periods of difficulties, such as negative side effects of treatment or when their child was to have a procedure that may influence the course of treatment. This roller coaster of emotions has been documented elsewhere in studies of childhood cancer (McGrath, 2002).

In describing their experience, the parents in the current study identified four main resources or qualities that helped them manage and ultimately transform the fear into a tolerable aspect of daily life. The four resources were being in the present, being strong, maintaining hope/faith, and making meaning. Other research has identified similar strategies. Dixon-Woods, Seale, Young, Findlay, and Heney (2003) noted seven similar qualities that were identified as being required by parents coping with childhood cancer: "strength, courage, love, the help of God, the ability to relish special moments, support of wider family and community, and access to specialist medical treatment" (p. 154). These qualities were the intentional, conscious strategies that parents employed on a daily basis in relation to the aspect of fear.

Being in the Present

Being present generally can imply two things: being in attendance, as in physically being here, or being present in a moment of time, as in now. The parents in present study for the most part made more reference to the latter meaning; they described

being in the present more as in taking one day at a time. Living in the present serves to

help one not focus on painful or fearful memories of the past or on anxieties and the

unknowns of the future. It is a way of feeling at peace and appreciating the presence of

those important to you. The following statements illustrate the parents' efforts to being in

the present:

> …my mom is a plan-in-advance person, but you can't do that; you just have to take one day at a time because you never know what's going to happen. (Sarah)

> That has helped both of us focus on nothing else but where we are now and where we're going; not ever looking back and not ever looking at what we could've done. (Cabell)

> …you take each day at a time. The possibility's out there, but, you know, who knows? You never know what's coming around the corner, so you take today, say we're going to enjoy it; we're going to be together, we might be in the clinic, but we're together. We'll go out to lunch afterwards and that'll be that. You get through each little step and that's how you do it. (Becky)

Being Strong

Being strong referred to the parents' sense that they either needed to hide their

fears from their child or family or to use the strategy of being strong as a way of keeping

their emotions under control so they could be a better parent for their child. They knew

that they needed to make decisions about treatment as well as make plans for the

management of their lives and the lives of their families outside of the clinic or hospital.

The following comments demonstrate the parents' sense of needing to be strong:

> You probably see me tearing up a little bit, but I never tear up [in front of son] because I never think of this...it's only now that we're talking about this that I'm thinking about it and me getting emotional because it's about helping him…he doesn't ever need to see fear in me. What he does need to see is intense love and support and hope. (Cabell)

Finally my dad, God bless him, he said, "You know you're going to have to get over this [fearfulness] in order for him to get better. You're going to have to get rid of this to focus on him." So as soon as we got the word, we started planning on what to do. We're going to find out what it is and we're going to kick its ass. We're going to take it down. (Katie)

My supervisor and all my co-workers said I got to be strong for him. (Gerry)

Maintaining Hope/Faith

Many parents described serendipitous events or experiences that, to them,

provided "proof" that their child was going to be okay. These interpretations were very

meaningful and helped parents maintain their hope and faith in a positive outcome, as

reflected in the following statements:

I prayed over the procedure and when we were leaving out, this nurse came up to me and at first I was a little worried because I was scared to go through this by myself because my mom wasn't there. So after I prayed on it and I was walking back into the room, a nurse came to me. She comforted me and she said, "Well, if you need someone to talk to, my name is Diane." And when she told me her name, I broke down because that's my mother's name. And so, you know, there were many of these little things that kind of gave you, like, everything's going to be fine. God is taking care of it all…there were so many moments that led to the peacefulness. (Gerry)

Sometimes I have a belief, when you get hit by that feeling that everything's alright. Then you get that quiver, this tingle all through your body and sometimes I get that and I know it's all cool…and it's reassuring. A positive flow. It lets me know I'm doing the right thing…you can't understand it…sometimes when you're feeling like at the end of it all, a person that you don't even know just smiles and says, "Hey," and it pulls you back and it's not so bad. (Matt)

It gives you a kind of feeling like, OK, every time you see another benefit or you see another kind of positive light, it gives you that feeling like, "OK, I'm doing the right thing. I'm on the right track." It's just a huge boost or empowerment. (Katie)

For other parents, their belief or faith was experienced more directly:

…I believe that every time I felt like maybe I was getting ready to falter or just getting tired or whatever, I knew that there were so many people praying and that all the powerful positive stuff coming our way would help us stay up and make it another day. Because I do believe in, I believe strongly in the power or prayer…whether you're Christian or Buddhist or whatever, sending good things that way. (Elizabeth)

Many studies have emphasized the importance of relying on spiritual support to help cope with stressful experiences.

Making Meaning

A sudden unexpected crisis, such as the diagnosis of cancer in a child, is felt more intensely because it challenges one's assumptions about what is fair, just, and predictable. Events that intuitively do not make sense motivate one to search for meaning in an effort to re-establish some sense of "all-rightness" in one's life. The search for making meaning is generally defined as a cognitive process that an individual engages in following an event that is stressful enough to create a disruption between the situational meaning and global meaning that has been constructed. Situational meaning refers to the perceptions one has in relation to a specific situation, whereas global meaning relates to perceptions regarding one's place in the world.

Skaggs and Barron (2006) conducted a comprehensive analysis of 30 years of research on the concept of meaning making in response to significant, negative life events. They found that, as a process, meaning making occurs when meaning congruence has been achieved. Meaning congruence takes place when a break no longer exists between the meaning that is initially ascribed to the significant and negative event and one's global meaning. Meaning congruence can be done either by changing the meaning of the event, which is done through reattribution and creating illusions, or by changing

global meaning. If the attempt to change situational meaning is not successful, one engages in techniques to change global meaning through positive reappraisal, problem-focused coping, and revaluing ordinary events. Of these techniques, positive reappraisal is most closely associated with benefit finding.

Every parent in the present study had worked to make meaning out of the event. Some had reflected on making meaning extensively, and some not much at all. Most infused the process with their spiritual or religious beliefs. Many of them said there was no way to make sense of what had happened to their child, but they could make meaning from the event. In this way, they felt an increased sense of control and a more positive sense of well-being. Following are some of the ways they expressed making meaning from their stressful experience:

> Sometimes I think that God make [sic] us to get through this difficulty. (Jung)
>
> That's what I said in the beginning, like what was the sign, what was this about, and I think it was that maybe I wasn't spending as much time with him. (Gerry)
>
> I don't know, but I think it is kind of, if we overcome this difficulty, then we can [be] better in other difficulties. (Jung)
>
> I'm not sure; I can't say that this happened for a reason. I don't know if it just happened maybe she was just born this way and why…I believe *in* something that happens, you know that God can work in our lives and I can learn and I can be a different person. (Sarah)

Finding Benefits

Folkman (2008) placed the concept of benefit finding as a strategy to help create meaning. She identified four strategies that individuals engage in following a traumatic or negative event in order to create meaning. Individuals will (1) infuse ordinary events with positive meaning; (2) find benefit, which reinforces positive beliefs about self and the

world; (3) relinquish untenable goals and substitute new goals; and (4) focus on what really matters and reorder priorities. Additionally, the literature on benefit finding has categorized the experiences into three main areas: a growth in character, a strengthening of relationships, and a gain in perspective.

Every parent interviewed for the current study easily identified and wanted to talk about the benefits they found throughout their child's cancer treatment. This would not be unusual if every parent had approached me knowing what the study was about. But 14 out of the 15 parents did not initially know what was being investigated. However, after I explained the study and asked them if they wanted to participate, all of them said they did. Many parents expressed gratitude at being able to talk about their experience and be reminded of some of the benefits, because many had not had benefits in the forefront of their awareness.

Benefit finding is empowering in that it increases the sense of inner strength and growth that helps one transform the fear. This process occurs over time in connection with being in the present and being strong.

Growth in Character

For the present study, growth in character refers to one feeling that he or she has become stronger, more patient, and more altruistic or feels he or she has grown as a person as a result of their experience. The parents not only reported this growth in themselves, but also related seeing these attributes in their children, both the one diagnosed with cancer and their other children, and in other family members.

Strength. The following statements illustrate the parents' reports of becoming

stronger as a result of the experience:

I think that I am definitely a stronger person. (Angie)

[Regarding her daughter, sibling of the child with cancer:] She's becoming a lot stronger. I was really worried about her initially, but she's got a lot more inner strength than I thought she had. (Teresa)

[Regarding her son, with cancer:] ASK [Association for the Support of Childhood Cancer] had a couple of events that we didn't really want to go to, but then we do and he brightens up and we see some of the Daniel he used to be and we say, "OK, let's just go and do this and bring back some of the old Daniel." And you look for the old child, but then again, you see how strong he is and you say, "OK, would you have been this strong if this had not been thrown this way?" Or, "If you can fight this as a 10-year-old, you're going to be unstoppable at 18. I'm not going to worry about sending you away to college because you can handle anything. If you can handle yourself in a room full of adults telling you what you need to do and you sit up and say, "No, I'm not doing that." So we're all getting stronger from all of this. (Teresa)

[Regarding Mark, her son with cancer:] He was always quiet and he's learned to become a self-advocate…he's taking charge and he's not afraid to say, "Hey, I need this or to question something." And that carries over to school and anywhere else. I think that's a big deal because he's always been shy. (Elizabeth)

This experience has made me stronger…has strengthened so many areas: faith, family bonds. You really can't explain it. (Tanya)

I've always known that I was pretty strong, but I have found a strength that I didn't even know that I had. (Emily)

I'm going to get a t-shirt made that says you can't scare me, my kid had cancer…it's not just me I don't think, but I do feel like this—I can take on pretty much anything because [of this]…so I feel like I can take this on and deal with it, I'm good to go. (Katie)

Patience. Regarding patience, one mother stated, "I've become more patient, I

know what's important" (Sarah).

Growth. In describing her personal growth throughout the experience, one mother noted, "And I am continuing to grow through the whole thing. I'm not finished by any stretch" (Katie). Another mother said, "I feel like I am different. I didn't go back to where I was. I changed a lot. I know I've grown…I don't know, maybe it's coming back and thinking, 'Well, you live and you have all these experiences' " (Sarah).

Altruism. The parents noted an increased sense of altruism in themselves and in other family members due to their experience. In describing her daughter, who is the sister of the child with cancer, one mother said that "she's started collecting money for the leukemia society, and she's growing her hair out for Locks of Love [a public nonprofit organization that provides hairpieces to financially disadvantaged children suffering from medical hair loss due to any diagnosis]," (Teresa). Another mother noted, "I'm more grateful; I say thank you to people all the time" (Katie). Similarly, another mother explained, "I feel more kind-hearted, and I have more compassion and empathy for people that have children with this" (Sarah).

Strengthening Relationships

Parents described an improvement in the quality of various relationships. They generally felt closer to their child with cancer as well as to other members of their family. They described deepening relationships with friends and the community as well as strengthening their spiritual or religious connections.

Child/Family. The following statements illustrate the parents' sense of improved relationships with their child and/or family members:

> …the actual time spent with him has increased. We've always had, I mean every minute has been quality time…but with this, I spend much more actual time with

him—physical hours—so that's been a benefit because we both learn from each other. (Cabell)

I think Mark and I are much closer; I mean we've always been a close family, but he was going through that teenage, puberty thing…and having to live in a hospital—it does make you get closer. I'd say that's one of the biggest things [benefits] is that we've gotten a lot closer. (Elizabeth)

I didn't think I could be any closer with him, but I am now. (Emily)

We [mother and son] were laying in the dark and started talking and he said, "I think more good has come out of this than bad." And I kind of think the same way. (Katie)

Yeah, like family. Family you haven't talked to in a while, they hear the news and it brings them closer; brings people closer. (Tanya)

It's made the family much closer…you realize she may not be here forever so you get closer and you appreciate what you have. (Sarah)

I feel like we're on top of it and we're doing well and we're actually thriving through it. And if we can do that, we can do anything. (Katie)

This has brought the family together in a big way…it got us closer in the sense that we all realize that we all matter and *it* matters—what's going on with the kid…. They're calling to check on me and Ben and, "Can we do anything, can we send anything?" (Matt)

What good did come is that he and his daddy did get closer. Him and his daddy had kind of a strenuous relationship. His daddy didn't spend time with him; he didn't think his daddy loved him. He never took up time with him and stuff like that…. But then he [the father] was at every doctor's visit. They did get closer. (Bridgette)

One thing I can tell you is I didn't have good relationship with my sister but, after my daughter got sick, my sister and I get very closer. (Jung)

I'm spending more time with him [Marcel] because of this…. That's what I said in the beginning, like, what was the sign, what was this about? And I think it was that maybe I wasn't spending as much time with him and now, when he got sick…so I think that's definitely been a good thing that came out of it. (Gerry)

Friends/Community. The parents also described stronger relationships with

friends and the community as a result of their child's cancer diagnosis:

> I guess you really learn how closely knit the community really is. We live in a small community and you know that there are people there but you didn't know how much people really cared. When she was first diagnosed, they brought flowers, gifts, cards…. (Angie)

> The wonderful things are that our community, everyone where I work, they have just stepped up; they've started bringing us meals, they've started connecting. (Teresa)

> After my daughter got sick, there are many friends, helpers for my family. (Jung)

Spiritual/Religious. The parents commented on an increased spiritual or religious

connection as a result of their experience. One mother stated, "I know I'm stronger as a

Christian" (Angie). Other participants noted an increased spiritual connection in others as

well as in themselves. For example, "I know that Chad has gotten closer to God because

of this" (Cabell); "I know she's [wife's] closer to God in her heart because of this"

(Matt); and, "My daughter made us closer to God" (Jung).

Gain in Perspective, Priorities

In describing their gain in perspective, parents talked about feeling clearer about

their life priorities, which influenced how they approached different situations. Events

that had previously seemed important now took a back seat to new areas. The parents'

sense of appreciation and gratitude was expanded and, as a result, they often made

changes in their lifestyles to reflect the authentic change they felt internally. The

following comments illustrate the parents' shift in perspective and priorities:

I guess you learn to see the world through different eyes. The little things that were major things before cancer aren't major, like the house being messy…. (Angie)

And the other thing is that that's the only thing that matters. Those little things don't matter. As long as he's healthy, I'm doing fine. (Tanya)

So that event [taking off work to let Ben see snow for the first time] was made more precious because of this situation. It's like a lot of things, that once you realize that you may not have something forever, it makes you realize how important these things are. (Matt)

I used to get all frustrated over little things then, in the big picture I say, "Wait, there is a lot of things going on and this is nothing; we can deal with this. This is not a big deal." I think about Sam and then I think, "This doesn't even matter." (Katie)

You see things differently…I've learned to look and think. Things aren't always the way you think…I used to see things so black and white, but now I don't think that way because of all the people I've met and seeing other sick kids (Sarah)

I think the things that used to bother me before, the little minor things, like him being hyper or something. Now I'm like, whatever. He's alive and he's better and I can handle when he's crazy and screaming. People must look at me and wonder, but I'm just happy he's alive and getting healthier. (Teresa)

I feel like one of the benefits we see, and I feel blessed, is that he doesn't have a more serious type of cancer. That's a benefit. We feel lucky. (Katie)

Re-evaluate lifestyles. The parents' experience with their child's cancer diagnosis

also caused them to re-evaluate their lifestyles and priorities, as demonstrated in the

following comments:

Like if the kids ask me to do something now and I'm in the middle of doing dishes or cleaning, now I stop and do that with them because you realize that time with your kids is more important than the house being clean or laundry being done. (Angie)

I know I have a problem with procrastinating and now, because of what has happened to him, you never know what is going to happen, that I guess I move toward things a little faster than what I used to…like my aunt is sick now and I make more effort…I try to stay kind of close to everybody. (Gerry)

I used to be a workaholic, but now that's not important. I can work and make money, but there's nothing that compares to the time I have with my son…what you do becomes what you are at some point. (Matt)

Summary

The theoretical model that was developed in this grounded theory study is a reflection of the process through which parents of children with cancer progress towards finding benefit in the experience. Within the context of being a parent, the participants' descriptions of their experiences ground this model in a manner that clearly represents how they actually lived through this event. Current research was used as supporting data to further strengthen this model. Parents' conveyed that the initial ordeal, which started their journey, was feeling overwhelmed with fear. This was the Basic Psychosocial Problem that parents dealt with as they incorporated intervening conditions such as getting information, getting support, having trust/faith, seeing their child improve, and the passage of time to get to a turning point. Many parents also described a specific instance, an epiphenomenon, which further helped them turn a corner. Turning a corner helped them transform their fear from being overwhelming to being manageable. This Basic Psychosocial Process was evident by their use of strategies such as being in the present, being strong, maintaining hope/faith, and making meaning. Through their making meaning of the event, they found benefit. The benefits the parents asserted were related to a growth in character, a strengthening of relationships, and a gain in perspective. Although each parent acknowledged feeling sad, angry, and fearful throughout their journey, each one expressed a gratitude for the benefits they felt had come from this experience.

CHAPTER 5

DISCUSSION AND IMPLICATIONS OF THE FINDINGS

The purposes of this study were to develop an understanding of the process of benefit finding in parents of children with cancer and to develop a theoretical model of parental benefit finding within the cancer experience. Given the gaps in what is known about the experience of benefit finding in parents of children with cancer and to deepen understanding of the phenomenon, a qualitative design was chosen to explore this process and the context within which this phenomenon occurs. Because the construct of benefit finding is considered a dynamic process and the focus for this study was on how benefit finding is experienced, grounded theory was the method of choice. The goal in using grounded theory for the present study was to obtain a deeper understanding of the many facets of the experience of benefit finding and to develop a conceptual model to organize and depict the constructs and structures that arise through the process of constant comparison analysis. The study answered the question, "What is the process by which parents of children with cancer come to find benefit within this experience?"

The process of benefit finding that emerged from the interviews was depicted in a theoretical model developed from the data. The Basic Psychosocial Problem that initiated the process was that of being overwhelmed with fear. The fears fell into three categories:

99

fear of the unknown, fear of their child dying, and fear of the parent losing all control.

Parents identified intervening conditions that helped move them from feeling

overwhelmed to feeling they could manage the fear: getting information, getting support,

having trust/faith, seeing their child improve, and the passage of time. These intervening

conditions led to a turning point—a transition from feeling overwhelmed to feeling they

could manage the situation. Many parents identified a specific event, an

"epiphenomenon," that helped create a turning point for them. This event, along with the

intervening conditions, moved the parent from being overwhelmed to being able to

manage/transform the fear, which was identified as the Basic Psychosocial Process. The

strategies parents identified that helped them manage the fear were (1) being in the

present; (2) being strong; (3) having faith/maintaining hope; and (4) making meaning out

of the event, of which benefit finding was the major component. The parents described

benefits that fell into three main categories: a growth in character, a strengthening of

relationships, and a gain in perspective. The entire process occurred within the context of

being a parent, because this awareness colored the entire experience.

In reviewing what was known about benefit finding in Chapter 2, one of the

ambiguities about the concept of benefit finding was how to categorize it. Benefit finding

has been conceptualized as a selective appraisal, as a coping strategy, and as a personality

characteristic. It has also been suggested that benefit finding may be viewed as a

reflection of growth or change, an explanation of one's temperament, a temporal

comparison, or as a manifestation of implicit change theory (Tennen & Affleck, 2002).

The results of the present study suggest that benefit finding falls within the realm of

meaning-focused coping. Parents reported finding benefit as they managed to transform their fears from being overwhelming to being manageable. Benefit finding helped parents balance out the negative stressors they experienced, helping them feel more in control and cope better.

Significance

A significant finding from this study that is relevant to nurses and other health care providers working with children with cancer and their parents is the information that came out about the intervening conditions. These intervening conditions were identified by the parents as necessary in helping them move from feeling overwhelmed to reaching a turning point. Getting information, getting support, having trust/faith, seeing their child improve, and the passage of time were found to be important to all parents.

For the parents in this study, getting information not only meant getting information about their child's diagnosis and treatment, but also entailed getting information about dealing with insurance, school involvement, social support services, the treatment protocol, medication, and procedural side-effects, as well as what to expect in general. Some parents obtained information from the Internet; others wanted limited information about prognosis, but focused more of their efforts in learning how to cope. Understanding that parents have different needs and that, given the high anxiety early in the treatment process, staff can tailor the information they give to the parents to best be heard and understood. Many parents in this study found printed information helpful, as well as the availability and willingness of the staff to answer questions.

Previous studies have documented the importance of getting support for parents of children with cancer (McCubbin, Balling, & Possin, 2002; Woodgate, 2003). These parents feel vulnerable and have emphasized the need to feel that the staff cares about their child and about them. Support from the health care team was identified as important by 88% of participants in the qualitative study conducted by McCubbin et al. (2002) on resiliency factors in parents of children with cancer. Their findings reflected three major components to this support: providing reassurance and realistic hope, being accessible for providing information and assistance, and showing respect for the parents. These findings were reflected in the model developed from data in the study reported here as contributing to the process in which parents came to find benefit. McCubbin et al.'s findings further support the model developed in this current study in that support from family, the community, and the workplace was also identified as important.

Additionally, connecting parents of newly diagnosed children with parents whose child is further along in the treatment process was found to be helpful by many of the parents in the present study. These connections helped the parents feel that they were not alone and gave them hope in the process. Encouraging parents to reach out and accept help from their family, friends, and community can be an intervention supported by the medical staff that helps parents move toward a turning point.

Another variable in the transition from being overwhelmed by fear to managing the fear was that parents needed to have trust or faith in the staff, in the treatment, in their child, in themselves, and often in their religious or spiritual beliefs. Parents developed trust in the staff by how the staff presented themselves to the parents (being open and

honest in their communication), feeling supported by the staff, observing the staff providing competent and sensitive care to their child, and investigating the reputation of the staff over the Internet or from friends and family. Many parents did searches on the Internet to make sure that the hospital was identified as a good institution and that it was the best place for their child to be. Trusting the treatment came from trusting what the staff informed them about the outcomes and from connecting to other parents whose child had the same diagnosis. Again, many parents searched the Internet for information about the latest treatment and came to believe that their child was receiving the best care.

The majority of the parents in this study (12 out of 15) identified having faith in their religious or spiritual beliefs as crucial in helping them get through the early phase of their child's illness. Many even expressed the belief that they would not have survived without this faith. Their faith gave them hope, solace, and support. Many Americans use religion to help them cope with crises. Schuster et al. (2001) found that 90% of people in a national sample turned to their religion to help them cope following the 9/11 attacks on the United States. Gallup and Lindsay (1999) found that 67% of Americans identify their religion as a "very important" part of their lives. In the present study, the parents portrayed their reliance on religious beliefs during the initial stage of their child's cancer diagnosis as giving them the strength to cope with the news and as looking to their faith as a roadmap for direction on how to proceed. Faith helped many of the parents have confidence in their ability to get through the overwhelming period and to do what they had to do to care for their child.

Their roles as parents influenced the participants' need to trust that their child would respond positively to the treatment and that their child was strong enough to rise above the difficulties associated with treatment and survive the ordeal. The aspect of having trust and faith was closely associated with the condition of seeing their child improve, which happened with the passage of time. As parents, seeing their child as strong and seeing their child respond positively to the treatment seemed crucial to the parents' own sense of well-being. As treatment progressed and the parents came to know what to expect, they reported feeling less afraid and more in control.

Previous research has examined the relationships between the emotional adjustment of mothers of children with cancer and the emotional adjustment of their child. The results have been mixed. In separate studies, Kupst et al. (1995) and Manne et al. (1995) found that the positive emotional adjustment of mothers was predicted by the positive emotional adjustment of their children. However, Grootenhuis and Last (1997) found the opposite to be true: The emotional adjustment of parents was not related to the emotional adjustment of their children. In the current study, parents did not focus on the emotional state of their child; rather, they focused on their child's physical appearance and on the quantitative measurements, such as lab reports and x-rays, which provided "proof" of their child's improvement. The parents reported doing better themselves emotionally when their child was doing better physically.

For parents in the current study, the passage of time was an important factor in getting them to a turning point. Parents expressed how getting their child on a protocol, figuring out how the day-to-day tasks and functioning of the family would be handled,

and getting used to the demands of adjusting to their new situation all helped in moving them forward. McCubbin and VanRiper (1996) identified two phases in their Resiliency Model of Family Stress: adjustment, and adaptation. The adjustment phase occurs shortly after diagnosis, and the family relies on their usual patterns of functioning and coping strategies that they have used in the past. Families then move into the adaptation phase, which involves developing new patterns of coping and functioning as they incorporate social support resources. In the current study, parents identified factors that were necessary to help them move from feeling overwhelmed to getting to a turning point, which then allowed them to move into living with the experience and to use management strategies they identified.

As previously noted, some of the parents described a specific incident that they identified as the turning point for them. This event was termed an epiphenomenon in this study. An epiphenomenon represented a transformative moment in the parents' experience with their child's cancer. Some of the parents believed it was having their prayers heard by God or a Higher Power. Others felt it was an existential experience, outside of their control. The parents who described this experience all said it provided them with a sense of peace, which in turn helped them feel as if they could handle the stress and uncertainty of the situation. This experience has been described to some degree in a few studies. Barnhart (2005) conducted a phenomenological inquiry with mothers of children with disabilities who reported the experience of deep personal growth as a result of their parenting a disabled child. The mothers described themselves as more compassionate and self-confident as a result of this transformation. Goddard (2004) also

conducted a phenomenological study to explore the experience of women who had been traumatized and reported being transformed by the event. The study depicted two phases to the transformative experience: disintegration and reintegration. Disintegration was characterized by extreme anxiety and distress, as expressed through three themes: falling apart, questioning being, and turning points. The reintegration phase represented transcendence and personal transformation, which included the themes of restoring balance, tolerating uncertainty, and moving beyond. Goddard's findings appear similar to the experience described by the parents in the current study.

Smith (2006) conducted a national spiritual transformation study that involved over 1,000 participants. Smith's study found that approximately half of respondents reported having a spiritual/religious change that permanently affected their lives. Interestingly, when examining regional differences, 60% of respondents in the South reported this experience, the highest in the country. In looking at the specific event that led to this personal transformation, over 50% identified a death, illness, or accident of someone close to them as the significant precipitator. The majority (79%) of respondents did not identify a specific event (the epiphenomenon in the present study), although they did specify that there was a before and after period in which a spiritual/religious change occurred. In the present study, the parents who did not report experiencing an epiphenomenon still described turning a corner that allowed them to feel more in control and better able to cope with this experience.

After turning this corner, parents in the present study identified several factors that helped them manage or transform their fears on a daily basis. These management

techniques are similar to commonly identified coping strategies but are more focused in directly addressing their fear, which is the basic psychosocial problem. Most parents mentioned being in the present as a helpful strategy in managing their fear. Focusing on the here and now allowed parents to move beyond focusing on "why?" and kept them from becoming fearful about the future. In this way, they were also able to focus their attention on what they perceived to be the most important priority in their lives at that time, their ill child. Parents use this strategy to maintain hope in the present, where neither the past nor the future takes priority. In their study, McCubbin et al. (2002) found that "living in the present" was significantly correlated with healthier coping.

In the current study, being strong was also identified as an important strategy in transforming the fear. The concept of being strong has been supported in other studies of parents of children with cancer. McGrath (2002) conducted a phenomenologic study with 16 parents of children with cancer to explore their experiences in the early phase of treatment. She found that "despite such doubt and uncertainty, parents reported the desire to be strong for others. In particular, they indicated the need to be strong for their sick children, who they admired for their ability to cope" (p. 994). Dixon-Woods et al. (2003) conducted an analysis of newspaper accounts of parents of children with cancer and compared them to interviews the authors conducted with parents of children with cancer to contrast the differences. The researchers found that being strong was one of the characteristics described both in the newspaper reports and in the parents' personal accounts.

The strategy of making meaning in the context of dealing with stressful events has been explored extensively over the past decade. In their concept analysis of searching for meaning in negative events, Skaggs and Barron (2006) reviewed 85 studies, all of which were conducted with adults in a nonparental role. In the current study, the process by which parents of children with cancer engage in meaning making is consistent with these other studies. Meaning making, as mentioned previously, has been linked to posttraumatic growth, thriving, flourishing, and benefit finding. The ability to positively appraise an event and, thus, to find benefit within it has been shown to have significant effects on psychological functioning. Helgeson, Reynolds, and Tomich (2006) conducted a meta-analysis of benefit finding and growth in which they examined the relationship between benefit finding to physical and psychological health. They reviewed 87 crosssectional studies, six of which included parents as the respondents. Three of these six studies examined parents of children with various developmental disabilities (autism, Asperger syndrome, and Down syndrome); one included parents of an infant recently discharged from an intensive care unit; and two examined parents of children with cancer. Tarakeshwar and Pargament (2001) found that parents of children with autism who used positive spiritual coping techniques demonstrated higher scores on the Stress Related Growth Scale and lower levels of anxiety and depression. In another study, Pakenham, Sofronoff, and Samios (2004) examined 47 mothers of children with Asperger syndrome and found that positive maternal adjustment was correlated with the mother's ability to reinterpret events in a positive way. This study specifically looked at benefit finding in relation to positive adjustment.

King and Patterson's (2000) study followed 42 parents of children with Down syndrome for 2 years and found that feeling hopeful about the future enhanced the parents' subjective well being, even though they had acknowledged a number of losses. The researchers found that the parents, who were able to integrate the loss into their goals and lives, reported increased feelings of personal growth as well. Interestingly, personal growth and subjective well-being were not strongly correlated, and the authors suggested the two components may be independent of one another. This could be understood within the phenomenon of co-occurrence, which puts forth the model that negative and positive emotions occur at or near the same time (Folkman, 1997; Viney, Henry, Walker, & Crooks, 1989; Wortman & Silver, 1987). These authors suggest that the regulation of affect is associated with different types of coping.

Affleck, Tennen, and Rowe (1991) coined the phrase "benefit finding" in relation to positive appraisal of a stressful event. They followed 42 mothers whose infants had been hospitalized in a neonatal intensive care unit for a period of time. Following discharge, the researchers asked participants if they had found any benefits from their stressful experience. Seventy-five percent of the mothers identified at least one benefit, The researchers listed the benefits in categories very similar to those reported by the parents in the current study: "improved relationships with family and friends, the importance of keeping life's problems in perspective, increased empathy, positive changes in their personality, and the certainty that their child was now even more precious to them" (p.586). In a 6- to 18-month follow up, Affleck et al. found that the mothers who reported benefits demonstrated less distress and a brighter mood than

mothers who did not report benefits. The authors conclude that benefit finding "appears to anticipate emotional well-being and is not confounded by objective measures of the severity of the problem" (p.586). An interesting finding in Affleck et al.'s study was that the babies of the mothers who reported finding benefit scored higher on their developmental tests 18 months later.

Two studies that examined benefit finding and physical or psychological growth in parents of children with cancer showed similar results reported in other studies. Best et al. (2001) investigated the relationship between parental anxiety during their child's treatment for leukemia and posttraumatic stress symptoms after treatment ends. This longitudinal study involving 113 parents focused on distress; however, the authors used a measurement that included an aspect of benefit finding—the Posttraumatic Growth Inventory. They found that mothers who had higher scores on the Posttraumatic Growth Inventory also had higher anxiety and avoidance measures. This finding is similar to other studies and supports the concept of co-occurrence (Tedeschi & Calhoun, 1996).

The second study involving mothers of children with cancer focused specifically on benefit finding related to their child's stem cell transplantation. The authors, Rini et al. (2004), researched the course and predictors of benefit finding, specifically the children's medical risk, the mothers' dispositional optimism, and sociodemographic variables. They also examined the relationship between benefit finding and psychosocial adaptation in the mothers. The results showed that both optimism and the child's medical risk predicted benefit finding. Psychosocial adaptation was not predicted by the degree of benefit finding until optimism was placed as a moderator in the equation.

These studies, combined with others that have examined benefit finding and health related outcomes in other populations, indicate that people who engage in benefit finding report less depression and more positive well-being overall (Helgeson et al., 2006). As a related construct, positive affect has been found to influence biological responses, such as diurnal cortisol patterns, and these influences may be health protective (Steptoe, Gibson, Hamer, & Wardle, 2007).

Thus, people who are able to find benefit within a stressful situation may fair better than those who do not. Positive beliefs may also serve to facilitate the use of effective problem-focused coping, such as information gathering, decision-making, and evaluating outcomes, according to Aspinwall and MacNamara (2005).

<div align="center">Implications for Nursing Practice</div>

It would be imprudent to suggest that pediatric oncology nurses start conversations about benefit finding with parents of children undergoing treatment for cancer. Suggesting to parents that they look on the bright side cannot lessen the degree of fear and distress they experience. However, because many parents acknowledge finding benefits during this stressful event and having an understanding of the process they go through in order to find benefit, some suggestions may be made.

First, it is important to remember that, early in the cancer treatment process, parents often feel overwhelmed with fear and nurses can use their understanding of this fear to tailor interventions that would be most helpful at this time. Allowing parents to ask questions, giving information that is made as easy to understand as possible, and writing down for parents what to expect and who they may contact will help quell their

initial anxieties. Additionally, offering hope that is grounded in reality is an important role of the staff in helping parents whose children have been diagnosed with a life-threatening illness. In the present study, participants noted that staff referring parents to others who have experienced the same or similar feelings was helpful, as was referring parents to the social worker and chaplain for additional resources both within and outside of the hospital or clinic.

Other important things parents mentioned as helping them get to a turning point was their belief that they could trust the staff about the treatment their child would receive. Being open and honest, following through with commitments, and taking time to listen to the parents' fears and concerns is an important way to engender trust. Supporting parents' ability to trust themselves and their child was also seen as helpful and can be supported by nurses. Sharing in parents' joys and providing feedback about their child's improvement is a supportive intervention. Lastly, caregivers may find it helpful to remember that the passage of time affects all parents, that parental anxiety will mitigate, and they will turn a corner, getting to the point of transforming their fears.

Nurses who show respect for the different coping techniques parents use in dealing with their child's illness will support the parents' ability to find benefit in the situation. Personal coping techniques allow parents to discover that being in the present, being strong, and maintaining hope and faith help to manage fears more effectively. It may be helpful to share these coping strategies with parents, stating that others have found them to be helpful. However, it may also be helpful to acknowledge that parents

will travel along their own road when it comes to making meaning and finding benefits within this experience.

Limitations of the Study

This study is limited by several factors. The initial focus of the study was specifically on benefit finding, thereby guiding the participants in that direction. Thus, the theoretical model is not a comprehensive model of the totality of parents' experiences when their child has cancer. Rather, it is a substantive theory, meaning that it is applicable to a specific population within a given area about a particular aspect of parents' experience. Moreover, although the sample demographics were reflective of the overall population seen in an urban, National Cancer Institute designated cancer treatment center, the majority of respondents were White mothers. Additionally, 10 of the 15 participants identified themselves as religious, which may also have influenced the outcome, specifically the occurrence of the epiphenomenon and the role of faith in parents' experience of benefit finding. The model is therefore possibly more reflective of the experience of benefit finding for Southern, White, religious mothers of children with cancer.

Recommendations for Future Research

This study provided an understanding of how parents of children with cancer come to find benefits within this experience. In an effort to make the model more comprehensive, similar research in a larger, more diverse population of parents would be useful. It would be important to "tease out" more information about the subcategories based on gender, race, age, socioeconomic status, and other related variables. For

example, questions that focus on specific areas of social support would be helpful. These questions might include: What type of support do fathers vs. mothers, older vs. younger parents, etc., find most helpful and at what point in the trajectory? How do higher or lower levels of anxiety influence benefit finding? How much does the passage of time influence one's ability to perceive benefits?

Another interesting aspect to explore in future studies would be how the actual process of asking about benefit finding affects parents of children with cancer. Tennen and Affleck (2002) distinguished benefit finding from benefit reminding, which is when an individual intentionally reminds herself/himself of possible benefits related to a stressful experience. In the present study, the interview process itself may have been an intervention that triggered the participants to remind themselves of benefits, thereby supporting their ability to find benefits. Future research using interviews or discussions about benefit finding as an intervention to promote mindfulness of potential benefits may be useful. The effect of the intervention on psychological outcomes in parents could lead to more focused care for these parents.

On a larger, more conceptual scale, findings from the present study support the importance of shifting the focus of research to positive, potentially health-promoting psychological variables. The more traditional focus on pathology has provided important information regarding interventions that may be used after symptoms develop. Research that focuses on salubrious influences is important in that findings may lead to the development and implementation of interventions that prevent or mitigate dysfunction.

It would also be interesting to conduct further research into the experience of the epiphenomenon that was described by several parents in this study. Investigating the time points of its occurrence, the effect of this experience on parents over time, and the relationship between this experience and measures of psychological well-being may provide insight into the meaning the epiphenomenon holds for parents.

Summary

Benefit finding is a complex process. The theoretical model and substantive theory that emerged during the course of this study provides a way to understand this process in parents of children with cancer. It may illuminate what parents feel they need in order to cope with a stressful experience in a positive way. It is hoped that this research will lead to effective interventions to help parents of children with cancer to either maintain or gain a higher level of emotional and psychological functioning.

List of References

List of References

Abraído-Lanza, A.F., Guier, C., & Colón, R.M. (1998). Psychological thriving among
Latinas with chronic illness. *Journal of Social Issues*, *54*(2), 405-424.

Adams, D., & Deveau, E. (1988). *Coping with childhood cancer: Where do we go from
here?* Reston, VA: Reston Publishing Company.

Adler, N.E., Epel, E.S., Castellazzo, G., & Ickovics, J.R. (2000). Relationship of
subjective and objective social status with psychological and physiological
functioning: Preliminary data in healthy, white women. *Health Psychology, 19*(6),
586-592.

Affleck, G., & Tennen, H. (1996). Construing benefits from adversity: Adaptational
significance and dispositional underpinnings. *Journal of Personality, 64*, 899-922.

Affleck, G., Tennen, H., Croog, S., & Levine, S. (1987). Casual attributions, perceived
benefits, and morbidity following a heart attack: An eight-year study. *Journal of
Consulting and Clinical Psychology, 55*, 29-35.

Affleck, G., Tennen, H., Pfeiffer, C., & Fifield, J. (1988). Social comparisons in
rheumatoid arthritis: Accuracy and adaptational significance. *Journal of Social and
Clinical Psychology, 6*, 219-234.

Affleck, G., Tennen, H., & Rowe, J. (1991). *Infants in crisis: How parents cope with*

newborn intensive care and its aftermath. New York: Springer-Verlag.

Aitken, T.J., & Hathaway, G. (1993). Long distance related stressors and coping behaviors in parents of children with cancer. *Journal of Pediatric Oncology Nursing, 10*, 3-12.

Aldwin, C.M. (1999). *Stress, coping, and development: An integrative approach*. New York: Guilford.

Aldwin, C.M., & Revenson, T.A. (1987). Does coping help? A reexamination of the relationship between coping and mental health. *Journal of Personality and Social Psychology, 53*, 337-348.

Aldwin, C.M., & Sutton, K.J. (1998). A developmental perspective on posttraumatic growth. In R.G. Tedeschi & C.L. Park (Eds.), *Posttraumatic growth: Positive changes in the aftermath of crisis* (pp.43-63). Mahwah, NJ: Erlbaum.

Aldwin, C.M., & Yancura, L. (2004). Coping and health: A comparison of the stress and trauma literatures. In P.P. Schnurr & B.L. Green (Eds.), *Trauma and health: Physical health consequences of exposure to extreme* stress (pp. 99-125). Washington, DC: American Psychological Association.

American Cancer Society. (2007, February 21). *Detailed guide: Cancer in children. What is childhood cancer?* Retrieved April 27, 2008, from http://www.cancer.org/docroot/CRI/content/CRI_2_4_1X_Introduction_7.asp?sitearea

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.

Antoni, M.H., Lehman, J.M., & Klibourn, K.M. (2001). Cognitive-behavioral stress management intervention decreases the prevalence of depression and enhances benefit finding among women under treatment for early-stage breast cancer. *Health Psychology, 20*(1), 20-32.

Antonovsky, A. (1987). *Unraveling the mystery of health: How people manage stress and stay well.* San Francisco: Jossey-Bass.

Aspinwall, L.G., & MacNamara, A. (2005). Taking positive changes seriously. *Cancer, 104* (Suppl. 11), 2549-2556.

Barbarin, O.A., & Chesler, M.A. (1984). Coping as interpersonal strategy: Families with childhood cancer. *Family Systems Medicine, 2*, 279-289.

Barbarin, O.A., & Chesler, M.A. (1986). The medical context of parental coping with childhood cancer. *American Journal of Community Psychology, 14*, 221-235.

Barbarin, O.A., Hughes, D., & Chesler, M.A. (1985). Stress, coping, and marital functioning among parents of children with cancer. *Journal of Marriage and Family, 47*, 473-480.

Barnhart, J. M. (2005). Excavating the perspective and spiritual transformation of mothers raising children with disabilities. *Dissertation Abstracts International Section A: Humanities and Social Sciences, 66*(5-A).

Bearison, D.J., Sadow, A.J., Granowetter, L., & Winkel, G. (1993). Patients' and parents' causal attributions for childhood cancer. *Journal of Psychosocial Oncology, 11*, 47-61.

Benzies, K.M. (2001). Symbolic interactionism as a theoretical perspective for multiple

method research. *Journal of Advanced Nursing, 33*(4), 541-547.

Best, M., Streisand, R., & Catania, L. (2001). Parental distress during pediatric leukemia and posttraumatic stress symptoms (PTSS) after treatment ends. *Journal of Pediatric Psychology, 26*(5), 299-307.

Blotcky, A.D., Raczynski, J.M., Gurnitch, R., & Smith, K. (1985). Family influences on hopelessness among children early in the cancer experience. *Journal of Pediatric Psychology, 10*, 479-493.

Blumer, H. (1969). *Symbolic interactionism: Perspectives and method.* Englewood Cliffs, NJ: Prentice-Hall.

Bower, J.E., Kemeny, M.E., Taylor, S.E., & Fahey, J.L. (1998). Cognitive processing, discovery of meaning, CD4 decline, and AIDS-related mortality among bereaved HIV-seropositive men. *Journal of Consulting and Clinical Psychology, 66*, 979-986.

Brown, R.T., Kaslow, N.J., Hazzard, A.P., Madan-Swain, A., Sexson, S.B., Lambert, R., et al. (1992). Psychiatric and family functioning in children with leukemia and their parents. *Journal of the American Academy of Child Psychiatry, 31*, 495-502.

Bulman, R., & Wortman, C. (1977). Attributions of blame and coping in the "real world": Severe accident victims react to their lot. *Journal of Personality and Social Psychology, 35*, 351-363.

Calhoun, L.G., Cann, A., & Tedeschi, R.G. (2000). A correlational test of the relationship between posttraumatic growth, religion, and cognitive processing. *Journal of Traumatic Stress, 13*(3), 521-527.

Calhoun, L.G., & Tedeschi, R.G. (1998). Beyond recovery from trauma: Implications for

clinical practice and research. *Journal of Social Issues, 54*(2), 357-371.

Carver, C.S. (1998). Resilience and thriving: Issues, models, and linkages. *Journal of Social Issues, 54*(2), 245-266.

Carver, C.S., & Antoni, M.H. (2004). Finding benefit in breast cancer during the year after diagnosis predicts better adjustment 5 to 8 years after diagnosis. *Health Psychology, 23*(6), 595-598.

Cayse, L.N. (1994). Fathers of children with cancer: A descriptive study of their stressors and coping strategies. *Journal of Pediatric Oncology Nursing, 11*, 102-108.

Chenitz, C.W., & Swanson, J.M. (1986). *From practice to grounded theory: Qualitative research in nursing.* Menlo Park, CA: Addison-Wesley Publishing Co.

Chesler, M.A., & Barbarin, O.A. (1987). *Childhood cancer and the family: Meeting the challenge of stress and support.* Philadelphia: Brunner/Mazel, Inc.

Chinn, P.L., & Kramer, M.K. (1999). *Theory and nursing: Integrated knowledge development* (5th ed.). St. Louis, MO: Mosby.

Clegg, N.J. (1997). The relationship between parents' perceptions of coping, quality of family relationships, and selected sociodemographic and illness-related variables and family adaptation in families of children diagnosed with cancer. *Dissertation Abstracts International, 58*(1-B).

Cordova, M.J., Cunningham, L.L., & Carlson, C.R. (2001). Posttraumatic growth following breast cancer: A controlled comparison study. *Health Psychology, 20*(3), 176-185.

Cruess, D.G., Antoni, M.H., & McGregor, B.A. (2000). Cognitive-behavioral stress

management reduces serum cortisol by enhancing benefit finding among women being treated for early stage breast cancer. *Psychosomatic Medicine, 62*(3), 304-308.

Davis, C., Nolen-Hoeksema, S., & Larson, J. (1998). Making sense of loss and benefiting from the experience: Two construals of meaning. *Journal of Personality and Social Psychology, 75*, 561-574.

Dixon-Woods, M., Seale, C., Young, B., Findlay, M., & Heney, D. (2003). Representing childhood cancer: Accounts from newspapers and parents. *Sociology of Health & Illness, 25*(2), 143-164.

Eiser, C., & Havermas, T. (1992). Mothers' and fathers' coping with chronic childhood disease. *Psychology and Health, 7*, 249-257.

Eiser, C. Havermas, T., & Eiser, J.R. (1995). Parents' attributions about childhood cancer: Implications for relationships with medical staff. *Child Care Health Development, 21*, 31-42.

Evans, R., & Madsen, B. (2005). Transitioning from the neonatal intensive care unit to the pediatric intensive care unit. *Newborn & Infant Nursing Reviews, 5*(4), 188-193.

Evers, A.W.M., Kraaimaat, F.W., & van Lankveld, W. (2001). Beyond unfavorable thinking: The Illness Cognition Questionnaire for chronic diseases. *Journal of Consulting and Clinical Psychology, 69*(6), 1026-1036.

Fife, B., Norton, J., & Groom, G. (1987). The family's adaptation to childhood leukemia. *Social Science and Medicine, 24*, 159-168.

Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science & Medicine, 45*(8), 1207-1221.

Folkman, S. (2008). The case for positive emotions in the stress process. *Anxiety, Stress, & Coping, 21*(1), 3-14.

Fontana, A., & Rosenheck, R. (1998). Psychological benefits and liabilities of traumatic exposure in the war zone. *Journal of Traumatic Stress, 11*(3), 485-503.

Fortune, D.G., Richards, H.L., & Griffiths, C.E.M. (2005). Adversarial growth in patients undergoing treatment for psoriasis: A prospective study of the ability of patients to construe benefits from negative events. *Psychology, Health & Medicine, 10*(1), 44-56.

Frankl, V.E. (1985). *Man's search for meaning: An introduction to logotherapy*. Boston: Beacon Press.

Frazier, P., Conlon, A., & Glaser, T. (2001). Positive and negative life changes following sexual assault. *Journal of Consulting and Clinical Psychology, 69*(6), 1048-1055.

Fritz, G.K., & Williams, J.R. (1998). Issues of adolescent development for survivors of childhood cancer. *Journal of the American Academy of Child and Adolescent Psychiatry, 27*(6), 712-715.

Gallup, G., Jr., & Lindsay, D.M. (1999). *Surveying the religious landscape: Trends in U.S. beliefs*. Harrisburg, PA: Morehouse Publishing.

Garmezy, N. (1985). Stress resistant children: The search for protective factors. In J. Stevenson (Ed.), *Recent research in developmental psychopathology* (pp. 213-231). Oxford: Pergaman Press.

Gartstein, M.A., Short, A.D., & Vannatta, K., (1999). Psychosocial adjustment of children with chronic illness: An evaluation of three models. *Journal of*

Developmental & Behavioral Pediatrics, 20(3), 157-163.

Glaser, B.G. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.

Glaser, B.G. (1998). *Doing grounded theory: Issues and discussions.* Mill Valley, CA: Sociology Press.

Glaser, B.G., & Strauss, A.L. (1967). *The discovery of grounded theory*. Chicago: Aldine Publishing Company.

Goddard, N.C. (2004). Metamorphosis: Spiritual transformation as response to suffering and trauma. *Dissertation Abstracts International: Section B: The Sciences and Engineering, 65*(1-B).

Greenberg, H.S., & Meadows, A.T. (1991). Psychosocial impact of cancer survival on school-age children and their parents. *Journal of Psychosocial Oncology, 9*(4), 43-56.

Grootenhuis, M.A., & Last, B.F. (1997). Predictors of parental adjustment to childhood cancer. *Psycho-Oncology, 6*, 115-128.

Grootenhuis, M.A., Last, B.F., De Graaf-Nijkerk, J.H., & Van Der Wel, M. (1996). Secondary control strategies used by parents of children with cancer. *Psycho-Oncology, 5*, 91-102.

Hamburg, D.A., & Adams, J.E. (1967). A perspective on coping behavior: Seeking and utilizing information in major transitions. *Archives of General Psychiatry, 17*(3), 277-284.

Helgeson, V.S., Reynolds, K.A., & Tomich, P.L. (2006). A meta-analytic review of

benefit finding and growth. *Journal of Consulting and Clinical Psychology, 74*, 797-
816.

Hinds, P.S., Birenbaum, L.K., & Clarke-Steffen, L. (1996). Coming to terms: Parents'
response to a first cancer recurrence in their child. *Nursing Research, 45*(3), 148-
153.

Hoekstra-Weebers, J.E., Jaspers, J.P.C., & Kamps, W.A. (2001). Psychological
adaptation and social support of parents of pediatric cancer patients: A prospective
longitudinal study. *Journal of Pediatric Psychology, 26*(4), 225-235.

Horowitz, W.A., & Kazak, A. E. (1990). Family adaptation to childhood cancer: Sibling
and family system variables. *Journal of Clinical Child Psychology, 19*, 221-228.

Hutchinson, S.A. (1993). Grounded theory: The method. In P.L. Munhall & C.O. Boyd
(Eds.), *Nursing research: A qualitative perspective* (pp. 180-212). New York:
National League for Nursing Press, Pub. No. 19-2535.

Iles, J.P. (1979). Children with cancer: Healthy siblings' perceptions during the illness
experience. *Cancer Nursing, 2*(5), 371-377.

Janoff-Bulman, R. (1992). *Shattered assumptions: Toward a new psychology of trauma*.
New York: Free Press.

Janoff-Bulman, R., & Berg, M. (1998). Disillusionment and the creation of value: From
traumatic losses to existential gains. In J.H. Harvey (Ed.), *Perspectives on loss: A
sourcebook* (pp. 35-47). Philadelphia: Brunner/Mazel, Inc.

Janoff-Bulman, R., McPherson F., & Frantz, C. (1997). The impact of trauma on
meaning: From meaningless world to meaningful life. In M.J Power & C.R Brewin

(Eds.), *The transformation of meaning in psychological therapies: Integrating theory and practice* (pp. 91-106). Hoboken, NJ: John Wiley & Sons, Inc.

Katz, R.C., Flasher, L., Cacciapaglia, H., & Nelson, S. (2001). The psychosocial impact of cancer and lupus: A cross validation study that extends the generality of "benefit-finding" in patients with chronic disease. *Journal of Behavioral Medicine, 24*(6), 561-571.

Kazak, A.E. (2004). Research priorities for family assessment and intervention in pediatric oncology. *Journal of Pediatric Nursing, 21*(3), 141-144.

Kazak, A.E., & Barakat, L.P. (1997). Brief report: Parenting stress and quality of life during treatment for childhood leukemia predicts child and parent adjustment after treatment ends. *Journal of Pediatric Psychology, 22*(5), 749-758.

Kazak, A.E., Christakis, D., Alderfer, M., & Coiro, M.J. (1994). Young adolescent cancer survivors and their parents: Adjustment, learning problems, and gender. *Journal of Family Psychology, 8*(1), 74-84.

Kazak, A.E., & Meadows, A.T. (1989). Families of young adolescents who have survived cancer: Social-emotional adjustment, adaptability, and social support. *Journal of Pediatric Psychology, 14*, 175-191.

Kazak, A.E., Stuber, M.L., & Barakat, L.P. (1998). Predicting posttraumatic stress symptoms in mothers and fathers of survivors of childhood cancers. *Journal of the American Academy of Child & Adolescent Psychiatry, 37*(8), 823-831.

King, L.A., & Miner, K.N. (2000). Writing about the perceived benefits of traumatic events: Implications for physical health. *Personality and Social Psychology Bulletin,*

26(2), 220-230.

King, L.A., & Patterson, C. (2000). Reconstructing life goals after the birth of a child

with Down syndrome: Finding happiness and growing. *International Journal of*

Rehabilitation and Health, 5(1), 17-30.

Kobasa, S.C. (1987). Stress responses and personality. In R.C. Barnett, L. Biener, & G.K.

Baruch (Eds.), *Gender and stress* (pp. 308-329). New York: Free Press.

Kobasa, S.C., Maddi, S.R., & Kahn, S. (1982). Hardiness and health: A prospective

study. *Journal of Personality and Social Psychology, 42*(1), 168-177.

Koch, A. (1985). "If only it could be me": The families of pediatric cancer patients.

Family Relations, 34, 63-70.

Koocher, G.P., & O'Malley, J.E. (1981). *The Damocles syndrome: Psychosocial*

consequences of surviving childhood cancer. New York: McGraw-Hill.

Kramer, P.A. (1990). Conceptualizing wisdom: The primacy of affect-cognition relations.

In R.J. Sternberg (Ed.), *Wisdom: Its nature, origins, and development* (pp. 279-213).

New York: Cambridge University Press.

Kupst, M.J. (1984). Coping with pediatric leukemia: A two-year follow-up. *Journal of*

Pediatric Psychology, 9(2), 149-163.

Kupst, M.J. (1992). Long-term coping with acute lymphocytic leukemia in childhood. In

A.M. LaGreca, L.J. Siegel, J.L. Wallander, & E.C. Walker (Eds.), *Stress and coping*

in child health (pp. 242-261). New York: Guilford Press.

Kupst, M.J. (1994). Coping with pediatric cancer: Theoretical and research perspectives.

In D. Bearison & R.K. Mulhern (Eds.), *Pediatric pscyooncology*. New York:

Oxford.

Kupst, M.J., & Bingen, K. (2006). Stress and coping in the pediatric cancer experience. In R.T. Brown (Ed.) *Comprehensive handbook of childhood cancer and sickle cell disease: A biopsychosocial approach* (pp. 35-52). New York: Oxford University Press.

Kupst, M.J., Natta, M.B., Richardson, C.C., Schulman, J.L., Lavigne, J.V., & Das, L. (1995). Family coping with pediatric leukemia: Ten years after treatment. *Journal of Pediatric Psychology, 20*(5), 601-617.

Kupst, M.J., Penati, B., Debban, B., Camitta, B., Pietryga, D., Margolis, D., et al., (2002). Cognitive and psychological functioning of pediatric hematopoietic stem cell transplant patients: A prospective longitudinal study. *Bone Marrow Transplantation, 30*, 609-617.

Kupst, M.J., & Schulman, J.L. (1981). The CPI subscales as predictors of parental coping with childhood leukemia. *Journal of Clinical Psychology, 37*(2), 386-388.

Kupst, M.J., & Schulman, J.L. (1988). Long-term coping with pediatric leukemia: A six-year follow-up study. *Journal of Pediatric Psychology, 13*(1), 7-22.

Kupst, M.J., Schulman, J.L., Mauer, H., Morgan, E., Honig, G., & Fochtman, D. (1983). The psychosocial aspects of pediatric leukemia: From diagnosis through the first six months of treatment. *Medical and Pediatric Oncology, 11*(4), 269-278.

Kupst, M.J., Tylke, L., Thomas, L., Mudd, M.E., Richardson, C., & Schulman, J.L. (1982). Strategies of intervention with families of pediatric leukemia patients: A longitudinal perspective. *Social Work in Health Care, 8*(2), 31-47.

Lansky, S.B., Cairns, N.U., Hassanein, R., Wehr, J., & Lowman, J.T. (1978). Childhood cancer: Parental discord and divorce. *Pediatrics, 62*(2), 184-188.

Larson, L.S., Wittrock, D.A., & Sandgren, A.K. (1994). When a child is diagnosed with cancer: Sex differences in parental adjustment. *Journal of Psychosocial Oncology, 12*(1/2), 123-142.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.

Lechner, S.C., Zakowski, S.G., & Antoni, M.H. (2003). Do sociodemographic and disease-related variables influence benefit-finding in cancer patients? *Psycho-Oncology, 12*(5), 491-499.

Lewandowski, W., & Jones, S.L. (1988). The family with cancer: Nursing interventions throughout the course of living with cancer. *Cancer Nursing, 11*(6), 313-321.

Lieberman, M.A. (1992). Limitations of psychological stress model: Studies of widowhood. In M.L. Wykle, E. Kahana, & J. Kowal (Eds.), *Stress and health among the elderly* (pp. 133-150). New York: Springer.

Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.

Luszczynska, A., Mohamed, N.E., & Schwarzer, R. (2005). Self-efficacy and social support predict benefit finding 12 months after cancer surgery: The mediating role of coping strategies. *Psychology, Health & Medicine, 10*(4), 365-375.

Magni, G., Messina, C., DeLeo, D., Mosconi, A., & Carli, M. (1983). Psychological distress in parents of children with acute lymphocytic leukemia. *Acta Psychiatric Scandanavia, 68*(4), 283-288.

Magni, G., Silvestro, A. Carli, M., & DeLeo, D. (1986). Social support and psychological distress of parents of children with acute lymphocytic leukemia. *British Journal of Medical Psychology, 59*, 383-385.

Manne, S.L., Lesanics, D., Meyers, P., Wollner, N., Steinherz, P., & Redd, W. (1995). Predictors of depressive symptomatology among parents of newly diagnosed children with cancer. *Journal of Pediatric Psychology, 20*(4), 491-510.

Marky, I. (1982). Children with malignant disorders and their families: A study of the implications of the disease and its treatment on everyday life. *Acta Paediatrica Scandanavia, Supplement, 303*, 1-82.

Martinson, I.M., & Cohen, M.H. (1988). Themes from a longitudinal study of family reaction to childhood cancer. *Journal of Psychosocial Oncology, 6*, 81-98.

McCausland, J., & Pakenham, K. I. (2003). Investigation of the benefits of HIV/AIDS caregiving and relations among caregiving adjustment, benefit finding, and stress and coping variables. *AIDS Care, 15*(6), 853-869.

McCubbin, M., Balling, K., & Possin, P. (2002). Family resiliency in childhood cancer. *Family Relations, 51*(2), 103-111.

McCubbin, M., & VanRiper, M. (1996). Factors influencing family functioning and the health of family members. In S.M. Hanson et al. (Eds.), *Family health care nursing: Theory, practice, and research* (pp. 101-121). Philadelphia: F.A. Davis.

McGrath, P. (2002). Beginning treatment for childhood acute lymphoblastic leukemia: Insights from the parents' perspective. *Oncology Nursing Forum, 29*(6), 988-996.

McGrath P., Paton, M.A., & Huff, N. (2005). Beginning treatment for pediatric acute

myeloid leukemia: The family connection. *Issues in Comprehensive Pediatric Nursing, 28*(2), 97-114.

McGregor, B.A., Antoni, M.H., & Boyers, A. (2004). Cognitive-behavioral stress management increases benefit finding and immune function among women with early-stage breast cancer. *Journal of Psychosomatic Research, 56*(1), 1-8.

McGuffey, L.B. (2001). Benefit finding, medication adherence, and cortisol as mediators of spirituality, religiousness, and immune status in HIV-seropositive gay and bisexual men. *Dissertation Abstracts International, 62*(5-B).

McMillen, J.C., Smith, E.M., & Fisher, R.H. (1997). Perceived benefit and mental health after three types of disaster. *Journal of Consulting and Clinical Psychology, 65*(5), 733-739.

McWhirter, W.R., & Kirk, D. (1986). What causes childhood leukemia? Some beliefs of parents of affected children. *Medical Journal of Australia, 145*(7), 314-316.

Meissner, H.I., Anderson, D.M., & Odenkirchen, J.C. (1990). Meeting information needs of significant others: Use of the Cancer Information Service. *Patient Education & Counseling, 15*(2), 171-179.

Michael, S.T., & Snyder, C. R. (2005). Getting unstuck: The roles of hope, finding meaning, and rumination in adjustment to bereavement among college students. *Death Studies, 29*(5), 435-458.

Moch, S.D. (1989). Health within illness: Conceptual evolution and practice possibilities. *Advances in Nursing Science, 11*(4), 23-31.

Mohr, D.C., Dick, L.P., & Russo, D. (1999). The psychosocial impact of multiple

sclerosis: Exploring the patient's perspective. *Health Psychology, 18*(4), 376-382.

Morrow, G.R., Hoagland, A.C., & Carnrike, C.L.M. (1981). Social support and parental

adjustment to pediatric cancer. *Journal of Consulting and Clinical Psychology, 49*,

763-765.

Morrow, G.R., Hoagland, A.C., & Morse, I.P. (1982). Sources of support perceived by

parents of children with cancer: Implications for counseling. *Patient Counseling and

Health Education, 4*, 36-40.

Morse, J.M. (2001). Pearls, pith, and provocation: Exploring the technical aspects of "fit"

in qualitative research. *Qualitative Health Research, 11*(6), 841-847.

Mu, P. (2002). Families of children with cancer: The impact on anxiety experienced by

fathers. *Cancer Nursing, 25*(1), 66-73.

Mulhern, R.K., Fairclough, D.L., Smith, B., & Douglas, S.M. (1992). Maternal

depression, assessment methods, and physical symptoms affect estimates depressive

symptomatology among children with cancer. *Journal of Pediatric Psychology, 17*,

313-326.

Myers, D.G. (2000). The funds, friends, and faith of happy people. *The American

Psychologist, 55*(1), 56-67.

Nannis, E.D., Susman, E.J., Strope, B.E., Woodruff, P.J., Hersh, S.P., Levine, A.S., &

Pizzo, P.A. (1982). Correlates of control in pediatric cancer patients and their

families. *Journal of Pediatric Psychology, 7*, 75-84.

Neimeyer, R.A., & Levitt, H. (2001). Coping and coherence: A narrative perspective on

resilience. In C.R. Snyder (Ed.), *Coping with stress: Effective people and processes*

(pp. 47-67). New York: Oxford University Press.

O'Leary, V.E. (1998). Strength in the face of adversity: Individual and social thriving. *Journal of Social Issues, 54*(2), 425-446.

O'Leary, V., & Ickovics, J.R. (1995). Resilience and thriving in response to challenge: An opportunity for a paradigm shift in women's health. *Women's Health: Research on Gender, Behavior, and Policy, 1*(2), 121-142.

Pakenham, K., Sofronoff, K., & Samios, C. (2004). Finding meaning in parenting a child with Asperger syndrome: Correlates of sense making and benefit finding. *Research in Developmental Disabilities, 25*(3), 245-264.

Pakenham, K I. (2005). Benefit finding in multiple sclerosis and associations with positive and negative outcomes. *Health Psychology, 24*(2), 123-132.

Pargament, K. (1997). *The psychology of religion and coping: Theory, research, and practice*. New York: Guilford.

Park, C.L. (1998). Stress-related growth and thriving through coping: The roles of personality and cognitive processes. *Journal of Social Issues, 54*(2), 267-277.

Park, C.L., Cohen, L., & Murch, R. (1996). Assessment and prediction of stress-related growth. *Journal of Personality, 64*, 91-105.

Park, C.L., & Folkman, S. (1997). Meaning in the context of stress and coping. *Review of General Psychology, 1*(2), 115-144.

Patistea, E. (2005). Description and adequacy of parental coping behaviours in childhood leukaemia*. International Journal of Nursing Studies, 42*(3), 283-296.

Patterson J.M., Holm, K.E., & Gurney, J.G. (2004). The impact of childhood cancer on

the family: A qualitative analysis of strains, resources, and coping behaviors. *Psycho-Oncology, 13*(6), 390-407.

Pearsall, P. (2003). *The Beethoven factor: The new positive psychology of hardiness, happiness, healing, and hope*. Charlottesville, VA: Hampton Roads Publishing Company, Inc.

Peck, B. (1979). Effects of childhood cancer on long-term survivors and their families. *British Medical Journal, 1*, 1327-1329.

Pennebaker, J.W. (1995). *Emotion, disclosure and health*. Washington, DC: American Psychological Association.

Petersen, E. (1997). *Quality of life, resignation, and survival: A prospective investigation of 292 women treated for cancer—Described in terms of the theory of thriving*. Aarhus, Denmark: Psykologisk Institut, Aarhus Univeritet.

Polatinsky, S., & Esprey, Y. (2000). An assessment of gender differences in the perception of benefit resulting from the loss of a child. *Journal of Traumatic Stress, 13*(4), 709-718.

Powazek, D.M., Schyving-Payne, J., Goff, J.R., Paulson, M.A., & Stagner, S. (1980). Psychosocial ramifications of childhood leukemia: One year post-diagnosis. In J.L Schulman & M.J. Kupst (Eds.), *The child with cancer* (pp. 143-155). Springfield, MA: Thomas.

Pyke-Grimm, K.A., Degner, L., Small, A., & Mueller, B. (1999). Preferences for participation in treatment decision-making and information needs of parents of children with cancer: A pilot study. *Journal of Pediatric Oncology Nursing, 16*(1),

13-24.

Ramsey, J.L., & Blieszner, R. (2000). Community, affect, and family relations: A cross-cultural study of spiritual resiliency in eight old women. *Journal of Religious Gerontology, 11*(1), 39-64.

Rini, C., Manne, S., & DuHamel, K.N. (2004). Mothers' perceptions of benefit following pediatric stem cell transplantation: A longitudinal investigation of the roles of optimism, medical risk, and sociodemographic resources. *Annals of Behavioral Medicine, 28*(2), 132-141.

Rowland, J.H., Mariotto, A., Aziz, N.A., Tesauro, G., Feuer, D., Blackman, D., et al. (2004). Cancer survivorship: United States, 1971-2001. *Morbidity and Mortality Weekly Report, 53*(24), 526-530.

Ruccione, K.S., Waskerwitz, M., Buckley, J., Perin, G., & Hammond, G.D. (1994). What caused my child's cancer? Parents' responses to an epidemiology study of childhood cancer. *Journal of Pediatric Oncology Nursing, 11*(2), 71-84.

Rutter, M. (1987). Psychosocial resilience and protective mechanisms. *American Journal of Orthopsychiatry, 57*, 316-331.

Saakvitne, K.W., Tennen, H., & Affleck, G. (1998). Exploring thriving in the context of clinical trauma theory: Constructivist self development theory. *Journal of Social Issues, 54*(2), 279-299.

Sakaguchi, Y. (2002). The role of meaning in the psychological process of bereavement: An examination of benefit finding effect. *Japanese Journal of Psychology, 73*(3), 275-280.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8*(3), 27-37.

Sarton, M. (1993). *Invocation to Kali: Collected poems* (pp. 326). New York: W.W. Norton & Company.

Schnurr, P.P., Rosenberg, S., & Friedman, M. (1993). Change in MMPI scores from college to adulthood as a function of military service. *Journal of Abnormal Psychology, 102*, 288-296.

Schuler, D., Bakos, M., Zsambor, C., Polcz, A., Koos, R., Kardos, G., et al. (1985). Psychosocial problems in families of a child with cancer. *Medical Pediatric Oncology, 13*, 173-179.

Schuster M.A., Stein, B.D., Jaycox, L.H., Collins, R.L., Marshall, G.N., Elliott, M.N., et al. (2001). A national survey of stress reactions after the September 11, 2001, terrorist attacks. *The New England Journal of Medicine, 345*(20), 1507-1512.

Shapiro, J., & Shumaker, S. (1987). Differences in emotional well-being and communication styles between mothers and fathers of pediatric cancer patients. *Journal of Psychosocial Oncology, 5*, 121-131.

Singer, B.H., & Ryff, C.D. (2001). *New horizons in health: An integrative approach.* Washington, DC: National Academy Press.

Skaggs, B.G., & Barron, C.R. (2006). Searching for meaning in negative events: Concept analysis. *Journal of Advanced Nursing, 53*(5), 559-570.

Sloper, P. (2000). Predictors of distress in parents of children with cancer: A prospective study. *Journal of Pediatric Psychology, 25*, 79-92.

Smith, T. (2006). The national spiritual transformation study. *Journal for the Scientific Study of Religion, 45*(2), 283-296.

Snyder, C.R., & Lopez, S. (Eds.). (2002). *The handbook of positive psychology*. New York: Oxford University Press.

Speechley, K.N., & Noh, S. (1992). Surviving childhood cancer, social support, and parents' psychological adjustment. *Journal of Pediatric Psychology, 17*, 15-31.

Spinetta, J.J., Murphy, J.L., & Vik, P. J. (1988). Long-term adjustment in families of children with cancer. *Journal of Psychosocial Oncology, 6*(3-4), 179-191.

Stanton, A.L., & Danoff-Burg, S. (2002). Emotional expression, expressive writing, and cancer. In S.J. Lepore & J.M. Smyth (Eds.). *The writing cure: How expressive writing promotes health and emotional well-being* (pp. 31-51). Washington, DC: American Psychological Association.

Steele, R. (2005). Strategies used by families to navigate uncharted territory when a child is dying. *Journal of Palliative Care, 21*(2), 103-110.

Steptoe, A., Gibson, E.L., Hamer, M., & Wardle, J. (2007). Neuroendocrine and cardiovascular correlates of positive affect measured by ecological momentary assessment and by questionnaire. *Psychoneuroimmunology, 32*, 56-64.

Streubert, H.J., & Carpenter, D.R. (1999). *Qualitative research in nursing: Advancing the humanistic imperative* (2nd ed.). Philadelphia: Lippincott Williams & Wilkins.

Stuber, M.L., Gonzales, S., Meeske, K., Guthrie, D., Houskamp, B.M., Pynoos, R., et al. (1994). Post-traumatic stress after childhood cancer: A family model. *Psycho-Oncology, 3*, 313-319.

Tarakeshwar, N., & Pargament, K.I. (2001). Religious coping in families of children with autism. *Focus on Autism and Other Developmental Disabilities, 16*(4), 247-260.

Taylor, S.E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist, 38*, 1161-1173.

Tedeschi, R.G., & Calhoun, L.G. (1995). *Trauma and transformation: Growing in the aftermath of suffering*. Thousand Oaks, CA: Sage.

Tedeschi, R.G., & Calhoun, L.G. (1996). The posttraumatic growth inventory: Measuring the positive legacy of trauma. *Journal of Posttraumatic Stress, 9*, 455-471.

Tedeschi, R.G., Park, C.L., & Calhoun, L.G. (1998). Posttraumatic growth: Conceptual issues. In R.G. Tedeschi, C.L. Park, & L.G. Calhoun (Eds.), *Posttraumatic growth: Positive changes in the aftermath of crisis* (pp. 1-22). Mahwah, NJ: Erlbaum.

Tennen, H., & Affleck, G. (2002). Benefit finding and benefit reminding. In C.R. Snyder & S. Lopez, (Eds.), *The handbook of positive psychology* (pp. 584-597). New York: Oxford University Press.

Tennen, H., Affleck, G., Urrows, S., Higgins, P., & Mendola, R. (1992). Perceiving control, construing benefits, and daily processes in rheumatoid arthritis. *Canadian Journal of Behavioral Science, 24*, 186-203.

Tomich, P.L., & Helgeson, V.S. (2004). Is finding something good in the bad always good? Benefit finding among women with breast cancer. *Health Psychology, 23*(1), 16-23.

Tringali, C.A. (1986). The needs of family members of cancer patients. *Oncology Nursing Forum, 13*(4), 65-70.

Urcuyo, K.R., Boyers, A.E., & Carver, C.S. (2005). Finding benefit in breast cancer: Relations with personality, coping, and concurrent well-being. *Psychology & Health, 20*(2), 175-192.

Verrill, J.R., Schafer, J., Vannatta, K., & Noll, R.B. (2000). Aggression, antisocial behavior, and substance abuse in survivors of pediatric cancer: Possible protective effects of cancer and its treatment. *Journal of Pediatric Psychology, 25*, 493-502.

Viney, L.L., Henry, R., Walker, B.M., & Crooks, L. (1989). The emotional reactions of HIV antibody positive men. *The British Journal of Medical Psychology, 62*, 153-161.

Walker, C.L., Wells, L., Heiney, S.P., Hymovich, D.P., & Weekes, D.P. (1993). Nursing management of psychosocial care needs. In G.V. Foley, D. Fochtman, & K.H. Mooney (Eds.), *Nursing care of the child with cancer* (2nd ed.). Philadelphia: WB Saunders.

Webster's New International Dictionary of the English Language. (1934). Springfield, MA: G. & C. Merriam Company.

Weiss, T. (2002). Posttraumatic growth in women with breast cancer and their husbands: An intersubjective validation study. *Journal of Psychosocial Oncology, 20*(2), 65-80.

Werner, E.E. (1989). High-risk children in young adulthood: A longitudinal study from birth to 32 years. *American Journal of Orthopsychiatry, 59*, 72-81.

Wittrock, D.A., Larson, L.S., & Sandgren, A.K. (1994). When a child is diagnosed with cancer: Parental coping, psychological adjustment, and relationships with medical personnel. *Journal of Psychosocial Oncology, 12*(3), 17-32.

Wong M.Y., & Chan S.W. (2006). The qualitative experience of Chinese parents with children diagnosed with cancer. *Journal of Clinical Nursing, 15*(6), 710-717.

Woodgate, R.L. (2003). A substantive theory of keeping the spirit alive: The spirit within children with cancer and their families. *Journal of Pediatric Oncology Nursing, 20*(3), 103-119.

Wortman, C.B., & Silver, R. (1987). Coping with irrevocable loss. In G.R. VandenBos & B.K. Bryant (Eds.), *Cataclysms, crises, and catastrophies: Psychology in action, Vol. 6* (pp. 189-235). Washington, DC.: American Psychological Association.

Younger, J.B. (1991). A theory of mastery. *Advances in Nursing Science, 14*(1), 76-89.

Appendix A

Flyer Describing Study's Aim and Distributed in Clinic

Study Participants Wanted

I am a doctoral student in the School of Nursing at Virginia Commonwealth University conducting research on the concept of benefit finding. Some parents of children with cancer have said that, although the experience has been frightening and stressful, they have experienced some positive things as well. I am looking for parents who are willing to talk with me about this experience.

What is required of you?

We will meet in a private room in the clinic for about an hour. With your permission, I will tape record our conversation. I will ask you questions about your experience, such as:

- Feeling the support of family, friends, or a spiritual source has been identified as a benefit by some parents of children with cancer. Can you tell me if you have experienced this and how it has affected you?
- How do you think this came about?
- Was there any part of this that was surprising or unexpected?
- Were you aware of doing anything different to help it along?
- Do you think it would have occurred had you not experienced this crisis with your child?

Do you think you would like to participate? If so, please call me at **784-9847**.

Thank you very much, Carol Zogran

Appendix B

Committee on the Conduct of Human Research Approval

V i r g i n i a   C o m m o n w e a l t h   U n i v e r s i t y

Office of Research
Office of Research Subjects
Protection

DATE: October 25, 2006

TO: Rita H. Pickler, PhD
          Maternal Child Nursing
          Box 980567

FROM: Ann Nichols-Casebolt, PhD
          Chairperson, VCU IRB Panel B
          Box 980568

BioTech Research Park, Building One
800 East Leigh Street, Suite 114
P.O. Box 980568
Richmond, Virginia 23298-0568

804 828-0868
800 828-1120
TDD: 1-800-828-1120

RE: **VCU IRB #: HM10529**
          Title: Exploring the Experience of Benefit Finding in Parents of Children with Cancer: A
          Grounded Theory Study

On October 25, 2006, the following research study was *__approved__* by expedited review according to 45 CFR
46.110 Categories 6 and 7. This approval reflects the revisions received in the Office of Research Subjects
Protection on October 25, 2006. This approval includes the following items reviewed by this Panel:

RESEARCH APPLICATION/PROPOSAL: NONE

PROTOCOL: Exploring the Experience of Benefit Finding in Parents of Children with Cancer: A
            Grounded Theory Study (received 10/25/06)

CONSENT/ASSENT:
  ▪ Research Subject Information and Consent Form (received 10/25/06, 4 pages)

ADDITIONAL DOCUMENTS:
  ▪ Flyer "Participants Needed" (received 09/14/06)

This approval expires on September 30, 2007. Federal Regulations/VCU Policy and Procedures require
continuing review prior to continuation of approval past that date. Continuing Review report forms will be
mailed to you prior to the scheduled review.

This Institutional Review Board is in compliance with good clinical practices (GCP) as defined under the U.S.
Food and Drug Administration (FDA) regulations and the International Conference on Harmonization (ICH)
guidelines. Virginia Commonwealth University is approved by DHHS to conduct human subjects research under
a Federal Wide Assurance #FWA00005287. **All correspondence related to this research study must include**
the IRB protocol number and the investigator's name(s) to assist us in locating your file. Please note that
the CCHR number is no longer valid, if applicable.

The Primary Reviewer assigned to your research study is Elizabeth Ripley, MD. If you have any questions, please
contact Dr. Ripley at bripley@vcu.edu or 828-9682; or you may contact Dana Andrews, IRB Coordinator, VCU
Office of Research Subjects Protection, at dmandrews@vcu.edu or 828-3992.

Attachment – Conditions of Approval

an equal opportunity/affirmative action university

Conditions of Approval:

1. Conduct the research as described in and required by the Protocol.

2. Obtain informed consent from all subjects without coercion or undue influence, and provide the potential subject sufficient opportunity to consider whether or not to participate (unless Waiver of Consent is specifically approved or research is exempt).

3. Document informed consent using only the most recently dated consent form bearing the VCU IRB "APPROVED" stamp (unless Waiver of Consent or Waiver of Documentation of Consent is specifically approved).

4. Provide non-English speaking patients with a translation of the approved Consent Form in the patient's first language. The Panel must approve the translated version.

5. Obtain prior approval from VCU IRB before implementing any changes whatsoever in the approved protocol or consent form, unless such changes are necessary to protect the safety of human research participants. Any departure from these approved documents must be reported to the VCU IRB immediately as an Unanticipated Problem (see #7).

6. Monitor all problems (anticipated and unanticipated) associated with risk to research participants or others.

7. *Report Unanticipated Problems (UPs)* following the VCU IRB requirements and timelines detailed in the VCU IRB Written Policies & Procedures available at http://www.research.vcu.edu/irb/wpp/flash/wpp_guide.htm#VIII-7.htm

8. Obtain prior approval from the VCU IRB before use of any advertisement or other material for recruitment of study subjects.

9. Promptly report and/or respond to all inquiries by the VCU IRB concerning the conduct of the approved research when so requested.

10. All protocols that administer acute medical treatment to human research subjects must have an emergency preparedness plan. Please refer to VCU guidance on Emergency Preparedness Plans available at http://www.research.vcu.edu/irb/guidance.htm.

11. The VCU IRBs operate under the regulatory authorities as described within:
    a) U.S. Department of Health and Human Services Title 45 CFR 46, Subparts A, B, C, and D (for all research, regardless of source of funding) and related guidance documents.
    b) U.S. Food and Drug Administration Chapter I of Title 21 CFR 50 and 56 (for FDA regulated research only) and related guidance documents.
    c) Commonwealth of Virginia Code of Virginia 32.1 Chapter 5.1 Human Research (for all research).

062806

VCU Memo

DATE: August 14, 2007

TO: Rita Pickler, PhD
           Maternal Child Nursing
           Box 980567

FROM: Ann Nichols-Casebolt, PhD _ANC_
           Chairperson, VCU IRB Panel B
           Box 980568

RE: **VCU IRB #: HM10529**
           **Title: Exploring the Experience of Benefit Finding in Parents of Children with Cancer: A
           Grounded Theory Study**

On August 14, 2007, this research study was _**approved for continuation**_ by expedited review according to 45
CFR 46.108(b) and 45 CFR 46.109(e) and 45 CFR 46.110 Categories 6 and 7.

VCU IRB APPROVED CONSENT/ASSENT FORM (attached):
  ▪ Research Subject Information and Consent Form, received 7/31/07, version date 10/25/06, 4 pages

This approval expires on July 31, 2008. Federal Regulations/VCU Policy and Procedures require continuing
review prior to continuation of approval past that date. Continuing Review report forms will be mailed to you
prior to the scheduled review.

The Primary Reviewer assigned to your research study is Elizabeth Ripley, MD. If you have any questions, please
contact Dr. Ripley at bripley@vcu.edu or 828-9682; or you may contact Jennifer Rice, IRB Coordinator, VCU
Office of Research Subjects Protection, at jlrice@vcu.edu or 828-3992.

Attachment – Conditions of Approval

Conditions of Approval:

In order to comply with federal regulations, industry standards, and the terms of this approval, the investigator must *(as applicable):*

1. Conduct the research as described in and required by the Protocol.

2. Obtain informed consent from all subjects without coercion or undue influence, and provide the potential subject sufficient opportunity to consider whether or not to participate (unless Waiver of Consent is specifically approved or research is exempt).

3. Document informed consent using only the most recently dated consent form bearing the VCU IRB "APPROVED" stamp (unless Waiver of Consent is specifically approved).

4. Provide non-English speaking patients with a translation of the approved Consent Form in the research participant's first language. The Panel must approve the translated version.

5. Obtain prior approval from VCU IRB before implementing any changes whatsoever in the approved protocol or consent form, unless such changes are necessary to protect the safety of human research participants (e.g., permanent/temporary change of PI, addition of performance/collaborative sites, request to include newly incarcerated participants or participants that are wards of the state, addition/deletion of participant groups, etc.). Any departure from these approved documents must be reported to the VCU IRB immediately as an Unanticipated Problem (see #7).

6. Monitor all problems (anticipated and unanticipated) associated with risk to research participants or others.

7. Report Unanticipated Problems (UPs), including protocol deviations, following the VCU IRB requirements and timelines detailed in <u>VCU IRB WPP VIII-7</u>:

8. Obtain prior approval from the VCU IRB before use of any advertisement or other material for recruitment of research participants.

9. Promptly report and/or respond to all inquiries by the VCU IRB concerning the conduct of the approved research when so requested.

10. All protocols that administer acute medical treatment to human research participants must have an emergency preparedness plan. Please refer to VCU guidance on http:/www.research.vcu.edu/irb/guidance.htm.

11. The VCU IRBs operate under the regulatory authorities as described within:
    a) U.S. Department of Health and Human Services Title 45 CFR 46, Subparts A, B, C, and D (for all research, regardless of source of funding) and related guidance documents.
    b) U.S. Food and Drug Administration Chapter I of Title 21 CFR 50 and 56 (for FDA regulated research only) and related guidance documents.
    c) Commonwealth of Virginia Code of Virginia 32.1 Chapter 5.1 Human Research (for all research).

Appendix C

Consent

TITLE: Exploring the experience of benefit finding in parents of children with cancer: A grounded theory study.

VCU IRB NO.:

This consent form may contain words that you do not understand. Please ask the study staff to explain any words that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

PURPOSE OF THE STUDY
The purpose of this research study is to find out about how parents of children with cancer come to find benefit, or good, within this experience.

You are being asked to participate in this study because you have a child with cancer who is being treated at the Pediatric Hematology/Oncology Clinic at Virginia University Health System and you have identified yourself as someone who has found benefit in this experience.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT
If you decide to be in this research study, you will be asked to sign this consent form after you have had all your questions answered and understand what will happen to you.

In this study you will be asked to meet with a member of the research team, Carol Zogran, in a private room in the clinic for about an hour. During that time, she will first ask you some specific questions about your child and your family (age, type of cancer and what stage of treatment). Then, she will ask you about your experience with your child's cancer and any benefits, or positive things, you may have found as a result. The interview may start like this:

"Some parents of children with cancer have said that, although the experience has been frightening and stressful, they have also found benefits in this experience. Some of the benefits expressed by other parents have been feeling increased support from family or friends or a closer connection to God or a Higher Power.

- Can you tell me if you have experienced these feelings, or others related specifically to your child's cancer?
- How do you think this came about?
- Was there any part of this that was surprising or unexpected?
- Were you aware of doing anything different to help it along?
- Do you think it would have occurred had you not experienced this crisis with your child?"

The meetings will be tape recorded so we are sure to get all of the idea's expressed, but no names will be recorded on the tape.

APPROVED

Ms. Zogran may also, with your consent, go with you into private areas to watch your interactions with your child's caregivers. She may also, after these interactions have occurred, ask you some brief questions to help her to understand what you were thinking during these interactions as it relates to your experience of benefit finding.

Your total time involvement will be approximately one hour for the interview and no more than two additional hours spent with you during the clinic visit.

RISKS AND DISCOMFORTS
Sometimes talking about these subjects causes people to become upset. Some of the questions will ask about things that have happened that may have been unpleasant. You do not have to talk about any subjects you do not want to talk about, and you may stop the interview at any time. If you become upset, the study staff will give you names of the chaplain and social worker in the clinic, or an outside counselor to contact so you can get help in dealing with these issues. If the researcher is concerned about your safety or the safety of your child, she is required by law to report that concern to appropriate persons.

BENEFITS TO YOU AND OTHERS
You may not get any direct benefit from this study, but, the information we learn from people in this study may help us design better programs for parents and children with cancer.

COSTS
There are no costs for participating in this study other than the time you will spend in the interviews.

CONFIDENTIALITY
Potentially identifiable information about you will consist of interview notes and audiotapes of interviews. Data is being collected only for research purposes. Your data will be identified by ID numbers, not names, and stored separately from medical records in a locked research area. All personal identifying information will be kept in password-protected files and these files will be deleted at the completion of the study. Audiotapes will be kept in a locked file cabinet for 3 months after the study ends and will be destroyed at that time. Access to all data will be limited to study personnel.

We will not tell anyone the answers you give us; however, information from the study and the consent form signed by you may be looked at or copied for research or legal purposes by Virginia Commonwealth University.

What we find from this study may be presented at meetings or published in papers, but your name will not ever be used in these presentations or papers.

IF AN INJURY HAPPENS
Virginia Commonwealth University and the VCU Health System (also known as MCV Hospital) do not have a plan to give long-term care or money if you are injured because you are in the study.

APPROVED

10/25/2006

6-14-07 / ER / JR

2

If you are injured because of being in this study, tell the study staff right away. The study staff will arrange for short-term emergency care or referral if it is needed.

Bills for treatment may be sent to you or your insurance. Your insurance may or may not pay for taking care of injuries that happen because of being in this study.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

You do not have to participate in this study. If you choose to participate, you may stop at any time without any penalty. You may also choose not to answer particular questions that are asked in the study.

Your participation in this study may be stopped at any time by the study staff without your consent. The reasons might include:
- the study staff thinks it necessary for your health or safety; or
- administrative reasons require your withdrawal.

QUESTIONS

In the future, you may have questions about your participation in this study. If you have any questions, complaints, or concerns about the research, contact:

Rita H. Pickler, PhD, RN, PNP, Professor of Nursing
School of Nursing
Virginia Commonwealth University
730 East Broad Street
Richmond, VA 23219
(804) 828-0721

Mailing Address:
PO Box 980567
Richmond, VA 23298-0567

Or, you may contact:
Carol Zogran, MS, RN, PhD Candidate
1394 Manakin Road
Manakin-Sabot, VA 23103
(804) 784-9847

If you have any questions about your rights as a participant in this study, you may contact:

Office for Research
Virginia Commonwealth University
800 East Leigh Street, Suite 113

APPROVED

10/25/2006

8-14-07 / ER / JK

3

P.O. Box 980568
Richmond, VA 23298
Telephone: 804-827-2157

You may also contact this number for general questions, concerns or complaints about the research. Please call this number if you cannot reach the research team or wish to talk to someone else. Additional information about participation in research studies can be found at http://www.research.vcu.edu/irb/volunteers.htm.

CONSENT
I have been given the chance to read this consent form. I understand the information about this study. Questions that I wanted to ask about the study have been answered. My signature says that I am willing to participate in this study.

_____

Participant name printed

_____

Participant signature   Date

_____

Name of Person Conducting Informed Consent
Discussion / Witness (Printed)

_____

Signature of Person Conducting Informed Consent   Date
Discussion / Witness

_____

Investigator signature (if different from above)   Date

APPROVED

8-14-07 *EK* / *JR*

4

Appendix D

Data Collection Form – Demographic Sheet

Code No._____   Date:_____

Parent(s) Name:_____   Age:_____

Child's Age:_____

Diagnosis:_____

Date of Diagnosis:_____

Phase of Treatment:_____

Parent's Occupation_____

Parent's Highest Grade Completed_____

Other Concurrent Stressors:

   Financial:_____

   Emotional:_____

   Occupational:_____

   Family:_____

   Educational:_____

   Other:_____

Vita

CAROL E. ZOGRAN, Ph.D., R.N., C.S.
1394 Manakin Road
Manakin-Sabot, VA 23103
(804) 784-9847
czogran@aol.com

CLINICAL SPECIALIST-PSYCHIATRIC/MENTAL HEALTH NURSING

EXPERIENCE

MEDICAL AND COUNSELING ASSOCIATES, INC., Richmond, VA
September 2006 – Present
Psychotherapist in group practice providing individual and family therapy to adults. Specializing in grief, coping with cancer and other medical challenges. Teach relaxation techniques and stress management.

MICHAEL BICK, MD, Richmond, VA
September 2001 – Present
Psychotherapist in small psychiatric practice. Provide medication checks and individual therapy focusing on client strengths.

VIRGINIA COMMONWEALTH UNIVERSITY SCHOOL OF NURSING, Richmond, VA
May 2007 – August 2007
Adjunct Faculty teaching graduate level psychosocial nursing course.

BON SECOURS ST. MARY'S HOSPITAL, ONCOLOGY SERVICES, Richmond, VA
November 2005 – July 2007
Group Facilitator for women with cancer. Provided support groups, arranged for guest speakers as well as provided information and taught stress management, nutrition, and other concerns regarding self-care through the cancer experience.

VIRGINIA COMMONWEALTH UNIVERSITY SCHOOL OF NURSING, Richmond, VA
September 2001 – August 2004
<u>Research Associate</u> responsible for collecting recruitment and enrollment data for a National Institutes of Health sponsored stress-management grant of which Dr. Nancy McCain was the principal investigator. Provided a 10-week mind-body oriented intervention to HIV-positive adults and assisted with postintervention data collection.

THE MIND BODY MEDICAL CENTER AT BON SECOURS RICHMOND
THE WELLNESS CENTER, Richmond, VA
September 1989 – September 2000
<u>Program Clinician</u> responsible for coordinating and implementing the Medical Symptom Reduction Program for patients with chronic medical conditions. Taught the Relaxation Response, coping skills, and other stress-management techniques to improve self-management of their disease. Assisted in the development of the Cancer and Cardiac Wellness Programs. At the Wellness Center, role was of <u>Clinical</u> <u>Specialist</u> providing individual, group, and family therapy to clients with psychiatric and substance abuse issues within a day hospital setting. Provided emergency evaluations and EAP services as needed.

KOHLER, HUDSON, AND ASSOCIATES, Richmond, VA
April 1988 – December 1989
<u>Psychotherapist</u> in a small private group practice, providing individual, group, and family therapy to adults.

PSYCHIATRIC INSTITUTE OF RICHMOND, Richmond, VA
November 1986 – April 1988
<u>Director of Crisis Services</u> for private psychiatric hospital serving children and adolescents. Provided psychiatric assessments and referrals, crisis intervention, and brief cognitive-behavioral therapy to children, adolescents, and adults.

CALVERT MEMORIAL HOSPITAL, Prince Frederick, MD
November 1983 – January 1986
<u>Clinical Specialist</u> for in-patient mixed adult and adolescent unit. Responsible for the clinical development and supervision of nursing staff and provided direct care through individual, group, and family therapy.

EDUCATION

VIRGINIA COMMONWEALTH UNIVERSITY, Richmond, VA
September 2000 – May 2008
<u>Doctor of Philosophy in Nursing</u> with a focus in Healing. Area of specialization is in positive coping and pediatric oncology investigating the concept of "Benefit Finding" from both quantitative and qualitative perspectives.

HERBERT H. LEHMAN COLLEGE OF THE CITY UNIVERSITY OF NEW YORK, Bronx, NY
September 1979 – June 1981
<u>Master of Science in Nursing</u> obtained in Primary Care Nursing: Child and Adolescent Mental Health with a minor in consultation/education.

THE CATHOLIC UNIVERSITY OF AMERICA, Washington, DC
September 1975 – June 1978
<u>Bachelor of Science in Nursing</u>

ADDITIONAL TRAINING/EDUCATION/PRESENTATIONS

Poster presentation for the Southern Nursing Research Society, February 2008, entitled "Exploring the Experience of Benefit Finding in Parents of Children with Cancer: A Grounded Theory Study"

Poster presentation for the Southern Nursing Research Society, February 2004, entitled "Psychometric Testing of the Benefit Finding Scale"

Intensive training in Mind Body Medicine provided by the Mind Body Medical Institute at Beth Israel Deaconess Medical Center, Harvard Medical School, Boston, MA

Certification in Eriksonian Hypnosis and Brief Psychotherapy

Certificate in Bereavement Counseling (RTS)

Certificate in Family Systems Theory provided by the Groome Center, Washington, DC (Two-year postgraduate school in Bowen Therapy)

LICENSURE/PROFESSIONAL CERTIFICATIONS

Licensed as a Registered Nurse in Virginia

Licensed as a Psychiatric and Mental Health Clinical Nurse Specialist in Virginia

Certified Advanced Practice Registered Nurse, Board Certified in Adult Psychiatric/Mental Health Nursing through the ANCC

Member, Sigma Theta Tau, National Honor Society of Nursing

Member and Academic Scholarship Recipient, Phi Kappa Phi

Member, American Holistic Nurses' Association

5/08