

A GROUNDED THEORY STUDY OF PARENTAL CAREGIVERS WHO HAVE
CHILDREN IN TREATMENT FOR CANCER: KEEPING HOPE POSSIBLE

A Dissertation Submitted to the College of
Graduate Studies and Research
In Partial Fulfillment of the Requirements
For the Degree of Doctor of Philosophy
In the College of Nursing
University of Saskatchewan
Saskatoon

By

JILL M. G. BALLY

Copyright Jill M. G. Bally, December 2012. All rights reserved.

PERMISSION TO USE

In presenting this dissertation in partial fulfilment of the requirements for a Postgraduate degree from the University of Saskatchewan, I agree that the Libraries of this University may make it freely available for inspection. I further agree that permission for copying this dissertation in any manner, in whole or in part, for scholarly purposes may be granted by the professor or professors who supervised my dissertation work, or, in their absence, by the Head of the Department, or the Dean of the College in which my dissertation work was done. It is understood that any copying, or publication, or use of this dissertation, or parts thereof for financial gain shall not be allowed without my written permission. It is also understood that due recognition shall be given to me and to the University of Saskatchewan for any scholarly use of any material in my dissertation.

Requests for permission to copy or to make other use of material in this dissertation in whole or part should be addressed to:

Dean of the College of Nursing
University of Saskatchewan
Saskatoon, Saskatchewan (S7N 5E5)
Canada

OR

Dean
College of Graduate Studies and Research
University of Saskatchewan
107 Administration Place
Saskatoon, SK, S7N 5A2
Canada

ABSTRACT

Purpose: The overall purpose of this qualitative research study was to gain a clear understanding of the experience of hope for parents who care for their child who was receiving treatment for childhood cancer. Specifically, the objectives were: (a) to gain an interpretive understanding of the hope experience and processes of hope for parents who have children who are undergoing treatment for cancer; (b) to describe and define parental hope and significant related concepts for parental caregivers of children undergoing treatment for cancer within their context; and, (c) to construct a tentative substantive theory that is grounded in the experiences of parents who care for their child with cancer.

Research Design: Qualitative: Constructivist Grounded Theory.

Sample and Setting: The study sample included 16 parents who were caring for their children in treatment for cancer at a Western Canadian Cancer Centre.

Methods/Procedure: Using purposive theoretical sampling, 16 parents were invited to participate in this grounded theory study. Thirty three open-ended, in depth, face-to-face interviews were conducted using a flexible interview guide, and fourteen journals with daily entries over a two week period were collected. The interviews were audio-taped, and both the interviews and the journals were transcribed verbatim, organized and stored using ATLAS.ti software. Analysis of the data was conducted using Charmaz's (2006) constructivist grounded theory approach.

Findings: A developing, substantive grounded theory was constructed in which hope was identified as vital to parents of children who were in treatment for cancer. Parental hope was defined as an essential, powerful, deliberate, life sustaining, dynamic, cyclical process that was anchored in time, and was both calming and strengthening, and provided inner guidance through the challenging experience of preparing for the worst and hoping for the best. Parental hope

helped parents to maintain a positive attitude and to seek growth during their experience of caring for their child who was in treatment for cancer. The parents' main concern was 'fearing the loss of hope', and this was ameliorated by the basic social process of 'keeping hope possible' through accepting reality, establishing control, restructuring hope, and purposive positive thinking.

Conclusions: Parents journey through numerous transitions related to the treatment phase of cancer that causes feelings of uncertainty, anxiety, stress, and loss of control. To minimize these adverse experiences, nurses can support parents' ability to keep hope possible, and thus, to optimize their well-being by understanding, assessing, and supporting parental hope.

ACKNOWLEDGEMENTS

With reference to the support that PhD students receive, a friend said to me, “you know, ‘*It takes a village*’ is not just for kids!”. In my case, that sentiment holds true. The completion of this dissertation relied on the contributions, support, generosity, care, and attention of ‘a village’ of people, all of whom I would like to acknowledge and thank sincerely.

First and foremost, my gratitude goes to all the parents who graciously, generously, and openly shared their experiences, and intimate thoughts and feelings with me. Their unique and heart-felt stories will always have a place in my heart and will continue to inspire me as I proceed with my program of research to find more meaningful and effective ways in which to support them. Thank you to Dr. C. Mpofu, Rick Pryor, Shari Nickel, Heather Cattet, and Patti Blachford for their support in the recruitment of parents for this study.

I wish to thank Dr. Wendy Duggleby, my co-supervisor, whom I highly respect and regard for her mastery of grounded theory, expertise in hope research, and most importantly, her terrific balance of professional and ethical guidance that she provided with genuine care and concern. My thanks also goes Dr. Lorraine Holtslander, my co-supervisor, for her exceptional, gentle wisdom, expertise in qualitative research methods, and family nursing, and for always allowing me to ‘pop in’ on a whim. I appreciate their time, guidance, and ongoing encouragement throughout the research process. Special thanks are extended to Dr. N. Stewart, Dr. L. Stamler, and Dr. D. Rennie who acted as Chairpersons for my committee meetings throughout the course of my doctoral studies.

I would also like to thank my committee members including Dr. C. Mpofu, Dr. R. Thomas-MacLean, Dr. S. Spurr, and Dr. K. Wright. It has been a privilege to be a recipient of their support and their unique and expert guidance. Each has contributed excellent scholarly advice that has challenged, guided, and encouraged me. Sincere thanks to Eileen Zaigel for her

timely and expert transcription services, and to Tammy Morrison for her professional and efficient technical support.

I am most thankful to my family and friends for their unwavering support, encouragement, and love. To my parents, Judy and Joel Gajadharsingh, I owe a debt of gratitude. You have taught me the meaning of work ethic, instilled in me the value of higher, lifelong learning, and modeled unwavering morality. You have both given unending time to this dissertation in more ways than I can measure. Your support, guidance, encouragement, love and interest were always appreciated. Without your support, this work would not have been possible. I also thank my husband, Erick, and my beautiful children, Kali and Lauryn for providing me with the space and the time to complete my PhD. Specifically, I thank Erick for the timely lunch time phone calls and evening chats that kept me going when times were tough; Kali, for ‘writing’ along with me (even if it was highlighter art); and Lauryn for understanding when I couldn’t play Lego, critters, or house – you have scarcely known a time without graduate work in our lives. I also thank my many dear and highly valued friends who have kept me in their thoughts and who have always cheered me on: Cin, Sue, Claire, Carol, Cheryl, Shelley, Marcella, and Tracie. Without the lunches, coffees, and laughs along the way, it would have been a very lonely experience.

Lastly, I would like to thank those who provided financial support for this research which made the completion of this dissertation less stressful and much more timely. The study was funded in part by the Canadian Association for Nurses in Oncology (CANO/ACIO). Bursaries from the University of Saskatchewan College of Nursing and College of Graduate Studies (The University Graduate Scholarship) and the Saskatchewan Nurses Foundation (The Jean Mahoney Bursary and the Saskatoon City Hospital School of Nursing Alumnae) also supported my doctoral studies.

DEDICATION

The privilege of being a daughter, and the joy of being a mother are the two most profound life experiences with which I have been blessed. I dedicate this dissertation to my parents, Judy and Joel Gajadharsingh, and to my daughters, Kali and Lauryn. You have made me who I am.

In addition, this dissertation is presented in memory of my dear friend and ‘PhD partner’, Cheryl Williams.

You lifted my mind and spirit, and helped me to realize what was possible. Just like hope, you were my personal rainbow!

TABLE OF CONTENTS

PERMISSION TO USE.....	i
ABSTRACT.....	ii
ACKNOWLEDGEMENTS.....	iv
DEDICATION.....	vi
TABLE OF CONTENTS.....	vii
LIST OF TABLES.....	xii
LIST OF FIGURES.....	xiii
SECTION 1: Introduction and Review of the Literature.....	1
1.0 Introduction.....	2
1.1 Organization of the Dissertation.....	4
1.2 Review of the Literature.....	6
1.2.1 Introduction.....	6
1.2.2 Background.....	7
1.2.3 Methods.....	10
1.2.3.1 Data Sources and Study Selection.....	10
1.2.4 Results.....	11
1.2.4.1 Characteristics of the Studies.....	20
1.2.4.2 Critique of the Studies.....	21
1.2.4.3 Qualitative Designs of the Studies.....	25
1.2.4.4 Qualitative Methods of Data Collection.....	26
1.2.4.5 Qualitative Sampling.....	26
1.2.4.6 Qualitative Data Analysis.....	27
1.2.4.7 Quantitative Designs of the Studies.....	28
1.2.4.8 Quantitative Methods of Data Collection.....	28
1.2.4.9 Quantitative Sampling.....	29
1.2.4.10 Quantitative Data Analysis.....	29
1.2.5 Summary of the Methodologies.....	30
1.2.6 A Synthesis of the Findings of the Reviewed Studies.....	31
1.2.6.1 The Meaning of Hope for Parents.....	33
1.2.6.2 Factors that Influence Parental Hope.....	33
1.2.6.3 The Outcomes of Parental Hope.....	35
1.2.6.4 Descriptions and Definitions of Parental Hope.....	37
1.2.7 Summary of the Synthesized Findings.....	38
1.2.8 Implications for Future Research.....	39
1.2.9 Conclusion.....	40

SECTION 2: Methodology	42
2.0 Relationship of Section 2 to the Dissertation.....	43
2.1 Introduction.....	44
2.2 Purpose and Objectives.....	45
2.3 Research Questions	45
2.4 Research Approach	45
2.4.1 Setting	46
2.4.2 Study Sample	46
2.4.3 The Inclusion Criteria	47
2.4.4 Data Collection Procedures.....	49
2.4.4.1 Demographic Form.....	50
2.4.4.2 Face-to-face Initial Interviews.....	50
2.4.4.3 Follow-up Telephone Interviews.....	51
2.4.4.4 Journal Writing.....	51
2.4.4.5 Field Notes.....	52
2.5 Data Analysis	52
2.6 Factors Influencing the Study	55
2.7 Rigor	55
2.8 Ethical Issues	56
2.9 Relevance and Benefits.....	57
2.10 Knowledge Translation.....	57
2.11 Establishment of Career in Saskatchewan	58
2.12 Research Environment.....	58
2.13 Timeline.....	60
 SECTION 3: Manuscript 1 - VIEWING THE ART AND THE SCIENCE OF PEDIATRIC NURSING THROUGH THE LENS OF PARADIGMS: THE IMPACT ON HOPE FOR THE FUTURE.....	 62
3.0 Relationship of Manuscript 1 to the Dissertation.....	63
3.1 Abstract	64

3.2	Introduction	65
3.3	Paradigms and Parental Hope	66
3.3.1	Research Paradigms	66
3.3.2	Parental Hope and Nursing Research.....	68
3.4	A Critical Review of the Literature Using Paradigms	69
3.4.1	Positivist and Postpositivist Paradigms.....	70
3.4.2	Critical Theory Paradigm.....	74
3.4.3	Interpretive Paradigm.....	77
3.5	Implications for the Art and Science of Pediatric Nursing	82
3.6	How Does this Information Affect Nursing Practice?	85
 SECTION 4: Manuscript 2 - A GROUNDED THEORY STUDY OF THE HOPE EXPERIENCE OF PARENTAL CAREGIVERS WHO HAVE CHILDREN IN TREATMENT FOR CANCER: KEEPING HOPE POSSIBLE		86
4.0	Relationship of Manuscript 2 to the dissertation.....	87
4.1	Abstract	88
4.2	Introduction.....	89
4.3	Background.....	90
4.4	Method	94
4.4.1	Design	94
4.4.2	Sample.....	94
4.4.3	Data Collection.....	95
4.4.4	Data Analysis	96
4.5	Results.....	99
4.5.1	The Sample.....	99
4.5.2	The Context.....	101
4.5.3	The Definition of Parental Hope.....	102
4.5.4	The Factors Influencing Parental Hope.....	104
4.5.5	The Parents' Main Concern: Fearing the Loss of Hope	105
4.5.6	The Parents' Basic Social Process: Keeping Hope Possible	106
4.5.7	The Subprocesses of Keeping Hope Possible	106
4.5.7.1	Accepting Reality.....	107
4.5.7.2	Establishing Control.....	108
4.5.7.3	Restructuring Hope	109
4.5.7.4	Purposive Positive Thinking.....	110
4.5.8	Summary of the Model: Keeping Hope Possible.....	111

4.6 Discussion.....	113
4.6.1 The Definition of Parental Hope.....	113
4.6.2 Accepting Reality.....	116
4.6.3 Establishing Control.....	117
4.6.4 Restructuring Hope.....	119
4.6.5 Purposive Positive Thinking.....	121
4.7 Factors Influencing the Study.....	122
4.8 Implications for Practice and Research.....	123
4.9 Conclusion.....	124
SECTION 5: Manuscript 3 - PARENTAL NARRATIVES OF THEIR CARE GIVING EXPERIENCES WITH THEIR CHILDREN WHO ARE IN TREATMENT FOR CANCER: RESTITUTION, CHAOS, AND QUEST.....	125
5.0 Relationship of Manuscript 3 to the Dissertation.....	126
5.1 Abstract.....	127
5.2 Introduction.....	128
5.3 Background.....	130
5.4 Method.....	134
5.4.1 Design.....	134
5.4.2 Sample.....	134
5.4.3 Data Collection.....	135
5.4.4 Data Analysis.....	136
5.5 Findings.....	137
5.5.1 Participants.....	137
5.5.2 Narratives.....	139
5.5.2.1 Restitution Narratives.....	139
5.5.2.2 Chaos Narratives.....	142
5.5.2.3 Quest Narratives.....	145
5.6 Discussion.....	148
5.7 Factors Influencing the Study.....	152
5.8 Implications for Practice and Research.....	152
5.9 Conclusion.....	153

SECTION 6: Implications of the Findings, and Conclusions.....	155
6.0 Implications.....	156
6.0.1 Implications for Nursing Practice	156
6.0.2 Implications for Nursing Research	159
6.1 Overall Conclusions.....	160
7. LIST OF REFERENCES.....	165
8. APPENDICES	
8.0 Appendix A: Ethical Approval University of Saskatchewan.....	184
8.1 Appendix B Supporting Letter for Research	185
8.2 Appendix C Letter to Recruitment Collaborators.....	186
8.3 Appendix D Letter of Introduction for Parents.....	188
8.4 Appendix E Consent Form.....	190
8.5 Appendix F Demographic Form	193
8.6 Appendix G Interview Guide.....	194
8.7 Appendix H Guide to Keeping a Hope Journal for Parents	195
8.8 Appendix I: Research Brochure	196
8.9 Appendix J: Letter of Permission to Include Published Manuscript: <i>Viewing the Art and the Science of Pediatric Nursing Through the Lens of Paradigms: The Impact on Hope for the Future</i>	198

LIST OF TABLES

Table 1.1 Description of the Studies.....	12
Table 1.2 Guide to the Critique of a Quantitative Research Report	21
Table 1.3 Guide to the Critique of a Qualitative Research Report	23
Table 2.1 Timeline	61
Table 4.1 Example of the Coding Process	97
Table 4.2 Participant Characteristics	100
Table 5.1 Frank's (1995) Narrative Types	129
Table 5.2 Participant Characteristics	138

LIST OF FIGURES

Figure 1.1 Model of the Synthesis of the Characteristics, Factors that Give Rise to, and the Outcomes of Parental Hope	32
Figure 4.1 Model of the Basic Social Process of "Keeping Hope Possible"	111

SECTION 1

INTRODUCTION

**A GROUNDED THEORY STUDY OF PARENTAL CAREGIVERS WHO HAVE
CHILDREN IN TREATMENT FOR CANCER: KEEPING HOPE POSSIBLE**

1.0 Introduction

To develop a clear understanding of what hope is like for parents who have children in treatment for childhood cancer, a constructivist grounded theory design was used to explore parents' hope experiences. Specifically, the objectives were: (a) to gain an interpretive understanding of the hope experience and processes of hope for parents who have children who are undergoing treatment for cancer; (b) to describe and define parental hope and significant related concepts for parental caregivers of children undergoing treatment for cancer within their social context; and (c) to construct a tentative substantive theory that is grounded in the experiences of parents who care for their child with cancer.

The study proceeded following ethical approval from the Saskatchewan Behavioural Research Ethics Board on July 20, 2011 (Appendix A), and operational approval from the Saskatoon Cancer Centre on August 9, 2011. One revision relating to ethics was submitted on November 3, 2011 requesting that second interviews take place in person, as well as by telephone to provide parents with an option. Parents requested this change as they found it more convenient to interview in person at the cancer centre when their child was receiving treatment. This amendment was approved on November 11, 2011.

Data collection and analysis took place from August 9, 2011, through early September 2012, a period of 13 months. Sixteen participants took part in 33 interviews, and 14 hope journals were written over a two week period. Two participants were interviewed only once (and did not submit hope journals) because they did not return follow up contacts. Fourteen participants were interviewed a second time to follow up with the first interview, and three participants were interviewed a third time to validate the findings of the study. All three participants stated that the conceptualization of the theoretical model resonated with them, and it

described their hope experience well. One parent specifically stated that it was “exactly right”, and that it confirmed her experience.

While conducting this study, I engaged in a reflexive process of exploration personally, and with the data and the families with whom I had the privilege of working. It was a time of mixed emotions, triumphs and tribulations, but undoubtedly, it was a time of tremendous growth and development, both personally and academically. As a researcher, I had the privilege of hearing about many parents’ joy when they discussed family celebrations including Halloween, Christmas, Easter, and their children’s’ birthdays. I also shared in their sorrows when hospital stays were unplanned, lasted longer than anticipated, or when they received negative results about their child’s health. Through these many experiences, I learned about the strength and courage that hope provided for parents, and exactly what it meant when one said, ‘hope guides me’, or that ‘hope is the calm in the storm’. I learned that one can live through and survive a traumatic, life altering event, and that there is always hope. Specifically, I saw first-hand, the strength, the courage, and the hope of the human spirit.

I cannot even begin to compare my personal and academic challenges during the course of this research to those of the parents who participated in this study, but I can say, that like the parents, I experienced many transitions and related periods of uncertainty and stress. I was fortunate to have the support of my co-supervisors, family, and friends during these trying times. More than that, as I reflect on the research process and on the parents’ experiences, I learned how to experience, albeit vicariously, a new appreciation for life, my children, and family. This was an unexpected gift - a true blessing, and in many ways, it has changed the way in which I live my life. I feel honoured and so very privileged to have met so many wonderful parents who allowed me to share their experiences. Their strength, courage, and spirit continue to amaze and

inspire me. It is my hope that I have truly and adequately expressed their hope experiences and stories so that others may learn from them, and so that we all can better assist other parents and families in their health care experiences.

1.1 Organization of the Dissertation

This dissertation is organized and presented in a Manuscript-style format in which three manuscripts are presented and integrated. The first section includes an introduction to the overall dissertation research and a literature review. Since the proposal was initially approved by my dissertation committee, I have updated and revised the literature review. The literature review presents a methodological critique and synthesis of the findings from 14 research studies related to the hope of parents who have children with a variety of childhood illnesses to highlight what is, and what is not known about parental hope. Suggestions for future research are included in this manuscript, and a table of the research studies (Table 1.1), and two tables (Tables 1.2 and 1.3) presenting the format by which the qualitative and quantitative studies were evaluated are also presented.

The second section contains elements from the initial proposal for the study that were written in the future tense and originally followed the format of a Saskatchewan Health Research Foundation (SHRF) New Investigator Establishment Grant Application (2011). The proposal has been reformatted to meet the requirements of this dissertation. In this section, an overview of the research plan is presented and it includes the purpose and objectives of the study, the research approach (design, setting, sample, data collection, and analysis), ethical considerations, as well as a timeline. A supporting letter (Appendix B), a letter to the recruitment collaborators (Appendix C), a letter of introduction for parents (Appendix D), the consent form (Appendix E), demographic form (Appendix F), interview guide (Appendix G), guide for parents for keeping a

hope journal (Appendix H), and the research brochure (Appendix I) are included in the appendices at the end of the dissertation.

Section three contains the first manuscript titled: *Viewing the Art and Science of Pediatric Nursing Through the Lens of Paradigms: The Impact on Hope for the Future*. This manuscript presents a critical examination of the literature related to parental hope through the lens of paradigms, and suggests that a multiparadigmatic approach to understanding the complexities of parental hope is necessary. This manuscript was published in the *Journal for Specialists in Pediatric Nursing*. A letter of permission from the *Journal for Specialists in Pediatric Nursing* to include the published manuscript titled: *Viewing the Art and Science of Pediatric Nursing Through the Lens of Paradigms: The Impact on Hope for the Future* in my dissertation is included in Appendix J at the end of the dissertation.

Section four contains the second manuscript titled, *A Grounded Theory Study of Parental Caregivers who have children in treatment for Cancer: Keeping Hope Possible*. For submission, this manuscript will be reformatted using the author guidelines of the *Journal of Pediatric Oncology Nursing*, and will follow APA style (Sixth edition, 2009). This section is a presentation of the major findings of the constructivist grounded theory analysis. Tables depicting the participant characteristics (Table 4.1), the coding process (Table 4.2), and a figure illustrating the basic social process of 'Keeping Hope Possible' (Figure 4.1), are presented in this manuscript.

Section five contains the third manuscript titled *Parental Narratives of Their Care Giving Experiences with Their Children Who are in Treatment for Cancer: Restitution, Chaos, and Quest*. This manuscript will be reformatted using the author guidelines for submission to the *Journal of Pediatric Nursing*, and will follow APA style (Sixth edition, 2009). This manuscript

was a planned in-depth analysis of the data taken from a qualitative study, and it describes the unique nature of the parents' caregiving experiences as they cared for their child who was in treatment for cancer. The parents' stories were organized and categorized into Arthur Frank's (1996) three narrative types including restitution, chaos, and quest. Although parents presented their narratives in a similar chronological order, they reported varied experiences while caring for their child during cancer treatment. The narrative analysis provides an insider's perspective, and therefore, a clearer understanding of these parents' unique and complex experiences. In this manuscript, implications for nursing practice and research are discussed, followed by a brief conclusion. A table introducing and adapted from Frank's (1996) three narrative types (Table 5.1), and a table defining the participant characteristics (Table 5.2) are contained in this manuscript.

The final section, section six, consists of the implications of the findings, an overall conclusion, and the reference list.

1.2 Review of the Literature

1.2.1 Introduction

Parents of children who have been diagnosed with, and are in treatment for childhood cancer face a reality that is not only incomprehensible, but also devastating (Brody & Simmons, 2007; Nicholas et al, 2009). In addition, the months, the potential years of treatment, and the resulting uncertainty, life changes, family disruptions, and challenges to role functioning are formidable eventualities (De Graves & Aranda, 2008; McGrath, 2000). The result may include feelings of despair, hopelessness, stress, exhaustion, and poor health (Grootenhuis & Last, 1997; James et al., 2002). Consequently, nurses who care for parents who are caregivers of their children in treatment for cancer, must develop the ability to provide comprehensive, holistic,

family centered nursing care (Kylma & Juvakka, 2007). This care is dependent upon holistic assessments that consider the physical, psychosocial, and spiritual domains of parental health. Parental hope is an integral component of such assessments (Forte, 1997; Horton & Wallander, 2001; Kylma & Juvakka, 2007). However, given the limited knowledge about parental hope, nurses may find it to be difficult to understand, or assess.

A review of the current state of the scientific literature related to parental caregivers of children in treatment for cancer is necessary for informing and advancing current health care practice, and for offering direction and guidance for future research in pediatric oncology. Hence, the purpose of this manuscript is to report the results of a review of the current literature related to the hope of parental caregivers of pediatric clients in treatment for childhood cancer.

1.2.2 Background

Hope has been researched, discussed, and utilized within and across a number of disciplines such as theology, psychology, sociology, medicine, and nursing. The literature from these disciplines recorded a common theme in which hope was described as a unique, complex, and multidimensional construct that is important to human beings and a valuable psychosocial resource within patient populations (Snyder, 2000). Nursing scholars, Farran, Herth, and Popovich (1995), for example, identified hope as a key and unique experience of human beings. “It functions as a way of feeling, a way of thinking, a way of behaving, and a way of relating to oneself in one’s world” (p. 6). Psychologists describe the process of hope as creative, imaginative, and transformative, and it is complex and difficult to measure (Jevne, 1991). Jevne (1991), a psychologist, also stated that hope has a temporal aspect, is experienced in the cognitive realm, is relational, shared, and is present in all dimensions of one’s life. Nursing scholars, Dufault and Martocchio (1985) defined hope as a “multidimensional, process-oriented,

dynamic, life force characterized by a confident yet uncertain expectation of achieving a future good, which, to the hoping person is realistically possible and personally significant” (p. 380). In their metasynthesis of 14 qualitative research studies dealing with the hope of family members caring for a person with chronic illness such as cancer, Duggleby et al (2010) found that hope was important, independent of age, relationship, or setting. These nurse researchers defined hope as “transitional dynamic possibilities within uncertainty” (p. 148). This definition is useful because it is broad, independent of age and relationship, and highlights the dynamic nature of hope as well as the notion of uncertainty that is also prevalent in the literature related to parents and their hope. Together, the above mentioned findings support hope as being complex, multidimensional, and important to human beings.

Many researchers have suggested that hope is an important psychosocial resource in the face of adversity (Elliott, 2005; Farran, Herth, & Popovich, 1995; Snyder, 2000). For example, Taylor (2000) stated, “a hopeful approach to health may provide much needed strength and solace” (p. 368). Thus, hope has been described, generally, as a personal psychosocial response, but it has also been identified and examined as an important clinical construct in caregivers of adult and pediatric family members with cancer (Benzein & Berg, 2005; Borneman, Stahl, Ferrell & Smith, 2002; Connelly, 2005; De Graves & Aranda, 2008; and, Kirpilani, et al., 2000). Levels of hope have also been described as having significant, positive relationships with coping (Eapen, Mabrouk & Bin-Othman, 2008; Farran, Herth & Popovich, 1995; Herth, 1993; Jevne, 1991).

Current theories of hope emphasize the importance of understanding the actions, processes, and conditions of hope, especially for those dealing with difficult life circumstances (Farran, Herth, & Popovich, 1995; Jevne, 2005; Snyder, 2000). Parents who become caregivers

for their children in treatment for cancer, may experience disbelief, feelings of being overwhelmed, and exhaustion (Barrera et al., 2004; Sawyer, Streiner, Antoniou, Rice, & Baghurst, 2000; Sloper, 2000). Some studies have suggested that while some parents who care for their children with cancer, have reportedly coped well, many other parents suffered from anxiety, despair, stress, emotional instability, and disruption of family life and roles (Grootenhuis & Last, 1997; James, et al., 2002).

The importance of hope for parents of children who are in treatment for cancer is emphasized in three studies (Kylma & Juvakka, 2007; Liu & Yeh, 2010; Salmon et al., 2012). Moreover, hope emerged as an important finding in several studies describing the experience of parents of children with cancer and other chronic illnesses (Angstrom-Brannstrom, Norberg, Strandberg, Soderberg, & Dahlqvist, 2010; Bjork, Wiebe, & Hallstrom, 2005; Fletcher, Schneider, & Harry, 2010; Huang, Mu, & Chiou, 2008; Kars et al., 2010; Larson, 1998; Patistea, Makrodimitri, & Panteli, 2000; Wong & Chan, 2006). For example, Larson (1998) revealed that Mexican mothers caring for their children with disabilities described hope as essential to their optimistic caregiving, even in difficult or trying times.

Unfortunately, there are only a few research studies that focus specifically on the hope of parents who have children in treatment for childhood cancer. There are only three studies that focused on parents of children who were receiving treatment for cancer (Kylma & Juvakka, 2007; Liu & Yeh, 2010; Salmon et al., 2012). All three studies included participants who were parents of children in active treatment, whose treatment was completed, and who are survivors.

The purposes of this updated literature review were to gain an understanding of the current state of knowledge related to the hope of parents who have children in treatment for cancer. The literature search was repeated between May 2011 and August 2012, and new studies were

isolated and were included along with the original studies that were found between December 2010 and January 2011. The review includes a methodological critique and synthesis of the overall findings of the studies reviewed, identification of gaps in knowledge, and recommendations for future research.

1.2.3 Methods

1.2.3.1 Data sources and study selection. A literature review was conducted to find the scientific literature related to parental caregivers of children who were receiving treatment for cancer and their related hope experiences. The following inclusion criteria were used in selecting the studies in this review: (a) the studies had to be located in peer-reviewed journals between 1989 and 2012 and had to be written in English; (b) the studies had to deal with parents as caregivers for their children who were 18 years of age, or younger; (c) the child or adolescent with cancer had to be diagnosed with any type of cancer; and (d) the studies had to examine the hope of parental caregivers as part of its objective. Opinion, or discussion papers were eliminated, but both qualitative and quantitative studies were retained.

Electronic searches were conducted between May 2011 and August 2012, following a similar search done in December 2010 to January 2012. Five databases were searched including Medline, CINAHL, PsychINFO, Web of Science, and The Cochrane Library. In addition, a Google Scholar search and review of Pro Quest Dissertations and Theses was completed. The keywords, subject headings, and search terms included “advanced childhood cancer”, “neoplasms”, “family caregivers”, “parental caregiver”, “parents”, “mothers”, “fathers”, “pediatric oncology”, and “hope”. This search netted three research studies. Because of the paucity of research, the use of terms were ultimately broadened to include, “chronic illness”, “life limiting illness”, and “life threatening illness”, as well as individual words for pediatric

chronic illnesses such as “leukemia”, “soft tissue sarcomas”, “lymphomas”, “spina bifida”, and “cerebral palsy”. Following this expanded search, 11 research studies were identified. A secondary search was initiated by hand searching the reference lists of the included studies, resulting in no additional studies.

1.2.4 Results

A total of 318 studies were found, and each one was carefully read to determine its fit with the inclusion criteria. Only three of the studies examined the hope of parents who had children who were receiving treatment for cancer, although only some of the children in each of the study samples were in active treatment. The remaining 315 studies had to be excluded because the study samples were not composed of parents, did not involve children or adolescents in treatment for cancer (ages 0-18), or, the hope of parental caregivers was not a related variable intended for study.

Therefore, the inclusion criteria were expanded to include studies of parents with children who had any chronic life limiting (LLI) and life threatening illness (LTI). The decision to broaden the literature search was based on the potential similarities that may be present, as well as the insight that may be gained from the examination of the experiences of parents of children with LLIs and LTIs. According to the World Health Organization (WHO, 1998), illnesses such as HIV, cancer, advanced cancer, muscular dystrophy, and cystic fibrosis share many prevalent symptoms. In addition, the Association for Children’s Palliative Care (ACT, 2009), the International Children’s Palliative Care Network (ICPCN, 2008), and WHO (1998), for example, contended that children and adolescents with these conditions and their families had similar needs and required similar management including spiritual, psychosocial, physiological, and social support and care.

Because of the expanded inclusion criteria, 11 additional studies from the original 318 studies were selected for this review. Thus, a total of 14 studies on the hope of parental caregivers for pediatric clients with LLIs or LTIs were retained in this literature review. Two of these studies were new since the last search was conducted (Liu & Yeh, 2010; Salmon et al., 2012). These studies were summarized according to specific criteria including the study reference and country of origin, study purpose, population, design, instrument(s), and results (see Table 1.1).

Table 1.1 Studies Investigating Hope and Parents of Children with Chronic Illness (n=23)

Study Reference and Country of Origin	Study Purpose	Population	Study Design	Instrument	Results
Amendolia, B. (2010) •U.S.A •Nursing	To examine the concept of hope in parents who have critically ill newborns	19 articles	Concept analysis	Literature review using CINAHL, MEDLINE PsycLIT	Literature is sparse from perspective of hope and parents in NICU. Suggestions for future hope research provided. Neonatal nurses are provided with suggestions to foster hope.
*Angstrom-Brannstrom, Norberg, Strandberg, Soderberg, and Dahlqvist (2010) •Sweden •Nursing	To describe parent's narratives about what comforts their child who suffers from cancer.	9 parents (eight mothers and one father) of children aged three to 9 years undergoing their first treatment	Qualitative content analysis	Interviews	Five themes and several subthemes identified. Nurses provided hope through honest information, and commitment to achieve cure. Talking to other parents offered hope for their child's recovery and survival. Treatment and recovery had

					parents vacillating between despair and hope.
*Bjork, Wiebe, and Hallstrom (2005) •Sweden •Nursing	To discover the families lived experience when a child is diagnosed with cancer.	17 mothers, 12 fathers, five patients with cancer, and five siblings (17 families)	Hermeneutic phenomenology	Interviews	Parents describe a two-fold theme of ‘a broken life world’ and ‘strive to survive’. Family members strove to feel hope to reduce feelings of fear and powerlessness. Hope helped family members to acquire new knowledge, gain control, and maintain normalcy in their family life.
De Graves & Aranda (2008) • Australia • Nursing	To explore families of children with a relapse in cancer; to question what influences care; and to challenge current practices.	17 parents: 12 Mothers; and 5 Fathers of children aged 2-16 years with recurring childhood cancer	Prospective Critical Ethnography	In-depth interviews	Parents fluctuate between hoping for a cure and contemplating death as they face the uncertainty of their child’s prognosis. Uncertainty impacts decision-making and prognostic communications
*Eapen, Mabrouk, and Bin-Othman (2008) • Medicine • United Arab	To identify parental attitudes, children’s self-perception and families’	38 families with leukemia, 30 families with juvenile diabetes and 30 control	Cross-sectional	Arabic version of Harter’s Self Perception Profile for Children (SPPC), and the parent version.	Parental hope was one of the most important factors that contributed to improved coping in children with leukemia.

Emirates	coping in families who have children diagnosed with cancer.	subjects.			
*Eapen and Revesz (2003) • Medicine • United Arab Emirates	To identify psychosocial factors and illness variables that are associated with childrens' and parents' ways of coping with cancer.	38 cancer families.	Cross-sectional	Semi-structured interviews and Harter's Self-perception profile (Arabic version)	Parental hope is one factor that is integral to patients and families in coping with the cancer experience.
*Fletcher, Schneider, and Harry (2010) •Canada •Unknown	To examine the lived experience of mothers of children with cancer at diagnosis, during treatment and the period following.	9 mothers of children aged 9 months to 7 years of children with cancer, and three health care workers.	Phenomenology	In-depth interviews	Five subthemes of coping were identified, including hope. In part, hope offered mother's something to hold onto and strength in difficult times. It helped them to continue their journey. Mother's hoped their child would recover.

Forte (1997)	To study the meaning of hope in family caregivers of children with sickle cell anemia.	7 Female family caregivers of children with sickle cell anemia.	Phenomenology	Photo-interviewing	Four themes revealed include: connectedness, manifestations of normalcy, promotion of a therapeutic health care regimen, and anticipation of the future. Hope is multi-dimensional, dynamic, enduring and ever-changing process that enables family caregivers of children with sickle cell anemia to adapt to caregiving situations.
Horton & Wallander (2001) •U.S.A. •Unknown	To investigate social support and hope and how they relate to distress.	111 mothers of children aged 5-18 years with chronic physical conditions.	Cross-sectional study	Hope Scale Social Support Questionnaire-6 Brief Symptom Inventory	Hope and social support were negatively associated with distress in mothers. Perceptions of hope moderated the relationship between disability-related stress and maladjustment. Hope did not seem to mediate the relationship between social support and distress.
*Huang, Mu, and Chiou (2008) • Taiwan • Nursing	To explore how family resources assist a single parent family in caring for a child with cancer.	Five single mothers and four single fathers of children aged six-15 years who have cancer.	Phenomenology (Colaizzi)	Open-question interviews.	Five major themes were identified, including hope kindled by credible professionals. Parents never abandoned hope and always felt that there was hope for recovery

<p>*Kars, Grypdonck, Beishuizen, Meijer-van den Bergh, and van Delden (2010)</p> <ul style="list-style-type: none"> • The Netherlands • Nursing/ Medicine/ Psych/ Ethics 	<p>To identify the main factors that influence the transition from preserving life to letting go, from a parents point of view.</p>	<p>44 parents of children aged six months to 16 years with incurable cancer.</p>	<p>Grounded Theory (Charmaz)</p>	<p>Open interviews</p>	<p>Parents struggle between letting go and preserving life is influenced by many factors. Letting go is supported by a number of factors, including hope: hope relieved distress related to loss; in part hope helped parents to move towards preservation.</p> <p>Parents hoped for a future involving a more positive outcome than the one expected, and hoped for a cure. Hope changed over the course of illness from hope for a cure, to hope for stabilization to hope for no suffering and a peaceful death.</p> <p>Hope delayed confrontation with loss.</p>
<p>Kauser, Jevne, & Sobsey (2003)</p> <ul style="list-style-type: none"> • U.S.A. • Unknown 	<p>To study the hope in families with kids who have significant disabilities and to identify what facilitates hope.</p>	<p>19 parents of children aged 3-18 years with a variety of disabilities.</p>	<p>Case Study</p>	<p>Face-to-face and internet interviews</p>	<p>Hope was identified as a dynamic process that assisted parents to reframe their lives in view of their experience. Hope was shaped by both their inner and external resources.</p>

<p>Kirpilani et al. (2000)</p> <ul style="list-style-type: none"> • Canada • Medicine 	<p>To investigate parental hope and NPEs as predictors of quality of life in children and youth with spina bifida</p>	<p>121 parents of children aged 5-12 years, and 60 parents of adolescents aged 13-20 years with spina bifida</p>	<p>Cross-sectional Study</p>	<p>HRQL instrument Miller Hope Scale Neonatal physical examination</p>	<p>For both age groups parental hope was more strongly associated with health related quality of life than with current or neonatal health status.</p>
<p>Kylma & Juvakka (2007)</p> <ul style="list-style-type: none"> • Finland • Nursing 	<p>To describe hope in parents of youth with cancer.</p>	<p>9 parents of adolescents aged 12-17 years with cancer.</p>	<p>Descriptive exploratory</p>	<p>Focused in-depth interviews</p>	<p>Hope is a life promoting factor and implies an orientation towards the future. Hope is associated with the cancer patient, care, caregivers, finances, faith, others, and pets.</p>
<p>*Larson (1998)</p> <ul style="list-style-type: none"> • U.S.A • Unknown 	<p>To examine the subjective well-being of mothers who have children with disabilities</p>	<p>Six Mexican-origin mothers with children aged five to 11 years who have disabilities.</p>	<p>Case Study</p>	<p>In depth interviews and observation.</p>	<p>Sustaining hope was tenuous and essential for mothers in their maternal work. There was tension between mother's hope and their child's current circumstance which acted as a driving force to continue caring for their child. By understanding the tension and the link to hope, health care professionals can address emotional issues for these families.</p>

Liu & Yeh (2010)	To identify the characteristics of uncertainty and distress and if mothers differed on quality of life and hope.	200 mothers of children with cancer	Correlational Study	Parental Perception of Uncertainty Scale, the Symptom Checklist-35-Revised, the Short-Form 36 Health Survey, the Herth Hope Index, demographic form	Maternal hope alone did not predict four subgroups of mothers based on uncertainty and distress. Mothers with the lowest level of uncertainty and distress reported the best quality of life and had higher hope scores than the other three subgroups.
Mednick, Cogen, Henderson, Rohrbeck, Kitessa & Streisand (2007) • USA • Medicine	To explore the relation between hope and anxiety in mothers of children with Type 1 Diabetes.	75 mothers of children aged 2-5 years with Type 1 Diabetes Mellitus.	Cross-sectional	General and medical questionnaire The State-Trait Anxiety Inventory The Hope Scale	Hope has a strong inverse relationship with distress. Hope may help to protect against anxiety in mothers of very young children with Type 1 Diabetes.
*Patistea (2000) • Greece • Nursing	To examine parental reactions, and resources following a child's diagnosis of childhood leukemia.	41 mothers and 30 fathers of children with leukemia receiving therapy as outpatients (ALL and AML)(age of children unknown)	Qualitative content analysis.	Semi-structured interview and questionnaire	Among other processes, hope allowed the parents to accept the diagnosis, accept its implications and to keep caring for their child and family. Hope was the most helpful factor in facing the diagnosis of leukemia Hope is an important area for professional intervention and nurses should temper hope with reality.

Reder & Serwint (2009)	To examine hope for families and pediatric health care givers during a child's serious illness	12 bereaved parents (9 mothers; 3 fathers), 10 attending physicians, 8 pediatric residents, 9 pediatric nurses	Content Analysis	Focus Groups	Parents' identified their role as 'bearers of hope'. Hope aided in decision making. Health care workers acknowledged the importance of hope. Hope changes.
Salmon et al (2012)	To clarify how formal pediatric care givers manage parents' hope in practice and address parents' needs.	53 parents, and 12 oncologists	Qualitative study	Face-to-face interviews at 1-2, 6 and 12 months after diagnosis	Hope had a short term focus and interpersonal, being built on faith in the oncologist. Hope was also interpersonal.
Samson et al (2009) • Canada • Unknown profession	To describe the hope for parents of a child with DMD.	12 parents (7mothers, and 5 fathers) of children aged 7.5-17 years of age with DMD.	Phenomenology	Semi-structured Interviews	The experience of hope hails from the cognitive appraisal of DMD. Hope may help parents realize the initial crisis, sustain their adaptation, and prepare for their child's death.
Thampanichawat (2007) • Thailand • Nursing	To explore how primary caregivers dealt with problems in caring for children	27 Primary Caregivers (8 mothers; 6 fathers; 10 Grandmas; 1 Grandpa; and 1 aunt and uncle.	Grounded Theory	Open-ended interviews	Maintaining love and hope was necessary for the continuing process of caregiving.

	with HIV infection.				
Venning, Elliott, Whitford, & Honnor (2007)	To explore the impact of a child's congenital or acquired chronic illness on hope scores reported by children and parents.	79 parents (76% female) and 53 children between the ages of 8-17 years with the diagnosis of chronic illness.	Cross-sectional Design	The Child Hope Scale The Adult Hope Scale The Depression Anxiety Stress Scale The Generalized Self-Efficacy Scale The Systems of Belief Inventory	Children with chronic illnesses and parents reported lower scores than did those without chronic illness. Children's hope scores were higher when the illness was congenital and the inverse was true for parents. Parent's hope scores were predicted by self-efficacy and depression.

Note: An * indicates studies that did not define hope as a construct of intended study, but identified hope as a significant finding.

1.2.4.1 Characteristics of the studies. Of the 14 studies included in this review, 9 were qualitative and 5 were quantitative. These studies were conducted in a number of countries including two from Canada, Australia, and one from the U.K., Finland, Thailand, Taiwan, and six from the United States of America. The authors of the studies represented many disciplines including nursing, psychology, medicine, and two studies were conducted by interdisciplinary teams. Three studies investigated parental hope within the context of treatment for cancer, and 11 studies investigated parental hope within the context of a variety of other childhood LLI and LTIs.

1.2.4.2 Critique of the studies. A critique of the methodologies and the clarity with which the studies were presented was undertaken using Polit and Beck's (2008) guidelines for quantitative (see Table 1.2) and qualitative research reports (see Table 1.3). All the studies provided clear, logical explanations regarding the purposes and aims of their research, and the

selection of the methodology fitted well with the purposes and aims of each study. Each study presented relevant background information to establish the context within which the study took place. However, despite the presentation of relevant background literature, one quantitative study did not adequately define hope as a key concept/variable (Kirpalani et al., 2000). In addition, two qualitative studies did not clearly explain the conceptual underpinnings that informed the research (Reeder & Serwint, 2009; Thampanichawat, 2008).

Table 1.2 Guide to the Critique of a Quantitative Research Report

Element of Research Study	Basic Questions for Critique of Each Quantitative Study
<p>Introduction</p> <ul style="list-style-type: none"> - Statement of the problem - Hypotheses or Research Questions - Literature Review - Conceptual/theoretical framework 	<ul style="list-style-type: none"> • Clear and identifiable? • Significant • Congruent with paradigm and methods? • Explicitly stated with identification of key variables and sample? • Consistent with literature review and conceptual framework? • Up to date and provides evidence for research? • Synthesis of evidence related to research problem • Are key concepts defined conceptually? • Conceptual/theoretical framework present, or absence is justified
<p>Method</p> <ul style="list-style-type: none"> - Protection of Participants' Rights - Research Design - Population and Sample 	<ul style="list-style-type: none"> • Rights of participants safeguarded? • Externally reviewed • Given purpose, was the most rigorous design used? • Were number of data points appropriate? • Did the design minimize threats to internal and external validity? • Was population identified and described in

	<ul style="list-style-type: none"> • detail? • Was the best possible sample design used to minimize biases and achieve representativeness? • Was the sample size adequate? Was a power analysis completed?
- Data Collection and Measurement	<ul style="list-style-type: none"> • Were the operational and conceptual definitions congruent? • Were key variables operationalized appropriately? • Were instruments appropriate, and described adequately?
- Procedures	<ul style="list-style-type: none"> • Did data collection yield data that were reliable and valid? • Was bias minimized during data collection? • Were data collectors adequately trained?
Results	
- Data Analysis	<ul style="list-style-type: none"> • Did data analysis address each research question or test each hypotheses? • Were appropriate statistical measures used? • Was the most powerful analytical method used? • Were type 1 and type 2 errors minimized or avoided?
- Findings	<ul style="list-style-type: none"> • Are findings adequately summarized?
Discussion	
- Interpretation of the findings	<ul style="list-style-type: none"> • Are all major finding interpreted and discussed within the context of the study's conceptual framework and existing literature? • Are the interpretations consistent with the results and study limitations? • Is there a discussion related to generalizability of the findings?
- Implications/Recommendations	<ul style="list-style-type: none"> • Is there a reasonable and complete discussion regarding implications for practice and future research?
Global Issues	

- **Presentation**
 - **Researcher Credibility**
 - **Summary Assessment**
- Well organized, written, and detailed?
 - Are findings accessible to practitioners
 - Do researchers qualifications and experience enhance confidence in the findings?
 - Despite limitations of the study do the findings appear to be valid?
 - Does the study contribute meaningful evidence to the existing literature, and to practice?

Note: Table adapted from Polit and Beck (2008)

Table 1.3 Guide to the Critique of a Qualitative Research Report

Element of Research Study	Basic Questions for Critique of Each Qualitative Study
Introduction	
Statement of the problem	<ul style="list-style-type: none"> • Stated clearly and unambiguous? • Does the problem statement indicate need for the study? • Is problem significant? • Is there a good match between the problem, paradigm, tradition, and methods?
Research Questions	<ul style="list-style-type: none"> • Are the research questions clearly stated, consistent with the study's philosophy, conceptual framework, or ideological orientation?
Literature Review	<ul style="list-style-type: none"> • Is the related literature adequately summarized and does it provide a solid base for the new study?
Conceptual Underpinnings	<ul style="list-style-type: none"> • Are key concepts adequately defined conceptually? • Is the philosophical, underlying tradition, or conceptual framework explicitly stated and appropriate?
Method	
Protection of Participants' Rights	<ul style="list-style-type: none"> • Rights of participants safe guarded? • Externally reviewed?

Research Design and Research Tradition

Sample and Setting

Data Collection

Procedures

Enhancement of Rigor

Results

Data Analysis

Findings

Theoretical Integration

Discussion

- Is the research tradition congruent with the methods used for data collection?
- Was an adequate amount of time spent in the field? Were there enough contacts with participants?
- Was there evidence of reflexivity in the design?
- Was the sample and setting described in enough detail?
- Was the approach used to gain access to the sample and setting appropriate?
- Was the sample size adequate; was saturation achieved?
- Were the methods of gathering data appropriate? Was triangulation achieved?
- Was a sufficient amount of data gathered and in sufficient depth and richness?
- Were data collection and recording procedures adequately described? Were they appropriate?
- Were data collected in a way that reduced bias or behavioural distortions?
- Were the staff who collected data adequately trained?
- Were methods used to enhance trustworthiness, credibility, and audibility of the data and were those adequately described?
- Were the data management and analysis methods sufficiently described?
- Were data analysis methods compatible with the research tradition and the type of data collected?
- Did analysis lead to an appropriate 'product'?
- Were findings appropriately summarized and substantiated by excerpts and supporting arguments?
- Do the themes adequately capture the meaning of the data? Were the themes adequately conceptualized?
- Did the analysis yield an insightful and meaningful picture of the phenomena under investigation?

Interpretation of the findings	<ul style="list-style-type: none"> • Are the findings interpreted within an appropriate frame of reference? • Are the findings interpreted within the context of prior studies and are they consistent with the study's limitations.
Implications /Recommendations	<ul style="list-style-type: none"> • Are the implications of the study discussed?
Global Issues	
Presentation	<ul style="list-style-type: none"> • Was the report well organized and sufficiently detailed? • Was the report sufficiently rich and vivid?
Researcher Credibility	<ul style="list-style-type: none"> • Do the researchers' clinical, substantive, or methodological qualifications and experience enhance confidence in the findings? • Do the findings appear to be trustworthy?
Summary Assessment	<ul style="list-style-type: none"> • Does the study contribute meaningful evidence that can be used in practice?

Note: Table adapted from Polit and Beck (2008)

1.2.4.3 Qualitative design of the studies. Nine of the qualitative studies reported the research design that was used, and each design was congruent with its aims and research questions. Two studies demonstrated a lack of clarity in relation to their design. One study stated that it was part of a 'longitudinal qualitative study' (Salmon et al., 2012), and another study appeared to be a content analysis, but this was not clearly stipulated (Reder, & Serwint, 2009). The lack of clarity made it difficult to determine the adequacy of the research design, and potentially, to interpret the findings accurately. Of the 9 qualitative studies in this review, two were grounded theories, and the remainder of the studies included a phenomenological study, case study, exploratory descriptive study, longitudinal qualitative study, concept analysis, content analysis, and a critical ethnography.

1.2.4.4 Qualitative methods of data collection. Six of the nine studies revealed that ethical approval was obtained prior to the start of research. Seven studies used interviews to obtain data, one used a literature review, and another used focus groups. All, but two of the studies that used interviews to collect data, used face-to-face interviews. One study used a

combination of face-to-face, and internet interviews (Kauser, Jevne, & Sobsey, 2003), and the other study used both face-to-face and telephone interviews (Kylma & Juvakka, 2007). The telephone and internet style of interview posed the advantage of obtaining a more diverse sample, as well as convenience for parents, but it may have resulted in a reduced ability for observation and adequate field notes, thus potentially reducing the richness of the data collected. A variety of interview techniques were utilized, including open-ended, semi-structured, and in-depth interviews. Each study revealed that the researcher(s) were experienced in research interviewing, and the study that used focused groups stated that the facilitator was skilled. Overall, each study provided ample information to demonstrate adequately how data collection took place. The methods were appropriate for qualitative studies, and for research aimed at exploring parental hope.

1.2.4.5 Qualitative sampling. All nine qualitative studies reported obtaining written, informed consent. The sample size of the studies ranged from 9 to 53 participants and all included primary caregivers, except for one study that included bereaved parents, physicians, residents, and nurses (Reder & Serwint, 2009), and another that included parents and oncologists (Salmon et al., 2012). The determination for sample size was not made clear in any of the studies, although two studies briefly discussed saturation of their themes (Kylma & Juvakka, 2007; Thampanichawat, 2007). In the remaining studies, it was not clear whether, or not saturation was required, or sought. The selection of research participants was appropriate given the research questions, and recruitment procedures were explained in all studies. All samples were selected through purposive sampling. Only two studies revealed that some parents chose not to participate (De Graves & Aranda, 2008; Samson et al., 2009), although in both cases, parents' reasons for declining participation were not provided. In one case, parents were

recruited from various centres, or associations (Kauser, Jevne, & Sobsey, 2003). Overall, sample sizes appeared to be adequate according to frequently used references pertaining to qualitative research (Charmaz, 2006; Creswell, 2007; Morse, 1994). Unfortunately, this was not clearly stated by the authors of the studies. In addition, in all studies, the participants were sampled purposively, and therefore, they may have been more interested in their willingness to participate, or had more positive or negative experiences than the general population of parents. Therefore, they may not be representative of all parents in the same contexts. In addition, all samples relied more heavily on mothers than fathers. Those studies that included parents of children in treatment for cancer were comprised of samples of children in active treatment and survivors post treatment (Kylma & Juvakka, 2001), pediatric oncologists and parents (Salmon et al., 2012), and parents of children newly diagnosed with cancer, in active treatment, and those who had completed treatment (Liu & Yeh, 2010). Thus, the findings may not adequately represent the experiences of only those parents whose children were in active treatment.

1.2.4.6 Qualitative data analysis. Four studies analyzed data that were transcribed verbatim, and four studies described simply transcribing the data. All the studies provided verbatim quotes from the participants to support the authors' interpretations. In all but two studies (Reder & Serwint, 2009; De Graves & Aranda, 2008), the procedures for data analysis were clearly highlighted and were supported by references to well-known research authorities (Creswell, 2007; Lincoln & Guba, 1985). Lastly, only four of the nine studies included discussions about the methods in which they strove to ensure credibility and trustworthiness of the data (Forte, 1997; Kauser, Jevne, & Sobsey, 2003; Kylma & Juvakka, 2007; Thampanichawat, 2008). The other studies did not discuss how enhancement of rigor was

undertaken. As a result, it may be difficult to determine whether, or not systematic bias of interpretations was reduced or prevented, thus potentially rendering the findings untrustworthy.

1.2.4.7 Quantitative designs of the studies. All the quantitative studies reported using a cross-sectional, correlational research design, and this was appropriate for the research questions and hypotheses presented in each study. However, due to the nature of cross sectional designs, the findings may have been limited because of the dynamic, process-oriented nature of hope. All authors provided sufficient detail regarding the designs of the studies to enhance understanding of the conceptualization of each study.

1.2.4.8 Quantitative methods of data collection. A number of different hope scales and a variety of other instruments were used in the selected quantitative studies (see Table 1) including The Adult Hope Scale, The Miller Hope Scale, and the Trait Hope Scale, and there was congruence between the conceptual and operational definitions of hope in each study. However, the use of different hope scales made the synthesis of findings difficult because of the lack of consistency in defining hope as either a state, or a trait. Other variables such as psychological distress (Horton & Wallander, 2001), and anxiety (Mednick, et al., 2007) were not adequately defined, and therefore, it was not possible to determine if the conceptual and operational definitions were aligned. All measures were self-report, were mailed to the respondents in most cases, and were completed at home without observation which reveals issues of validity since the truthfulness of the answers of the respondents may not have been verified. Two studies did not provide sufficient detail to determine how data collection took place (Liu & Yeh, 2010; Venning, Whitford, Elliott, & Honnor, 2007).

1.2.4.9 Quantitative sampling. The sample sizes ranged from 75 to 200 participants who were sampled by convenience in all studies. Kirpialni et al (2000) purported to have used random

sampling, but the procedures related to randomization were not described. Convenience sampling may have limited the findings in all those studies because it would have been difficult to determine whether, or not, the parents in these studies were representative of all parents in that population. In almost every case, the samples consisted mainly of mothers, but examination of the father's experiences and perspectives were limited. Power analysis for sample size was discussed in only one study (Kirpilani et al., 2000), and therefore, it is unclear if the other studies had sufficient power to test their hypotheses. The findings, then, must be interpreted cautiously.

1.2.4.10 Quantitative data analysis. Each quantitative study addressed its research questions, or hypotheses adequately through data analysis and included descriptive statistics to describe their data sets. Analyses included regression analyses (Horton & Wallander, 2001; Kirpilani et al., 2009; Mednick et al., 2007), multiple regression and ANOVA (Venning, Elliott, Whitford, & Honnor, 2007), cluster analyses, chi square tests, independent t tests, and ANOVA (Liu & Yeh, 2010). Each of the studies utilized a computer software program to support data analysis. Overall, the discussion sections in the studies were relevant, and the authors were successful in tying together the hypotheses and literature review with their own significant findings. However, one study did not include a discussion of its limitations; the number of statistical tests undertaken and the potential for type 1 error, potential threats to validity regarding the characteristics of the sample, pertinent information related to the measure used, and recommended adjustments for future research (Lui & Yeh, 2010). A discussion of the limitations may have helped to guide future research as well as replication of the study with enhanced methods (Polit & Beck, 2008).

1.2.5 Summary of the Methodologies

The literature search related to the hope of parents with children who are in treatment for cancer provided a very limited number of studies. This alone revealed a gap in the extant literature base. When the inclusion criteria were expanded, studies were included that dealt with the hope of parents of children who had a variety of LLIs and LTIs and 11 more studies were selected. Together, these studies provided an important overview of parental hope. However, there were a number of methodological limitations that highlighted the need for future research. The qualitative studies provided an insider's perspective of the parents' hope experiences and the use of different methodologies provided a variety of insights. Some studies did not elaborate on the strategies that were undertaken to ensure credibility and trustworthiness, and therefore, the related findings had to be interpreted with caution. In addition, the samples of those qualitative studies that dealt with parents whose children were in treatment for cancer, were mixed and may not have adequately reflected their hope experiences during the active treatment phase. All the quantitative studies were cross sectional, and therefore, may have limited utility in identifying and examining the dynamic processes of hope that occur over time. Longitudinal studies are required to remedy this. There appeared to be only one study in which randomization was used as a sampling procedure, potentially limiting the representativeness of the samples, and only one study presented a power analysis to estimate sample size needs. Therefore, it is not known if the statistical conclusion validity in these studies was affected (Polit & Beck, 2008). A number of the quantitative studies did not adequately provide conceptual definitions of variables of interest such as anxiety, psychological distress, and stress. There were no mixed method studies conducted that may have been, in fact, well suited to the study of parental hope given their ability to combine the process oriented, explanatory potential of qualitative approaches with the statistical benefits of quantitative methods.

Finally, each study described parents who were caregivers for very specific and unique childhood illnesses. Nevertheless, the analysis of the studies revealed a number of interesting findings indicating that hope is indeed an important and useful construct for parents, and certainly underlines the necessity for additional research.

1.2.6 A Synthesis of the Findings of the Reviewed Studies

The findings from the reviewed studies were synthesized using four main categories. The categories were chosen based on those themes that appeared most commonly within the studies and included: the meaning of hope for parents; factors that influence hope; the outcomes of parental hope; and, descriptions and definitions of parental hope (see Figure 1.1). Nine additional studies were also included in the synthesis of the findings because of the large number of conclusions that related to hope as an important resource for parents as caregivers for their children with cancer (Table 1.1).

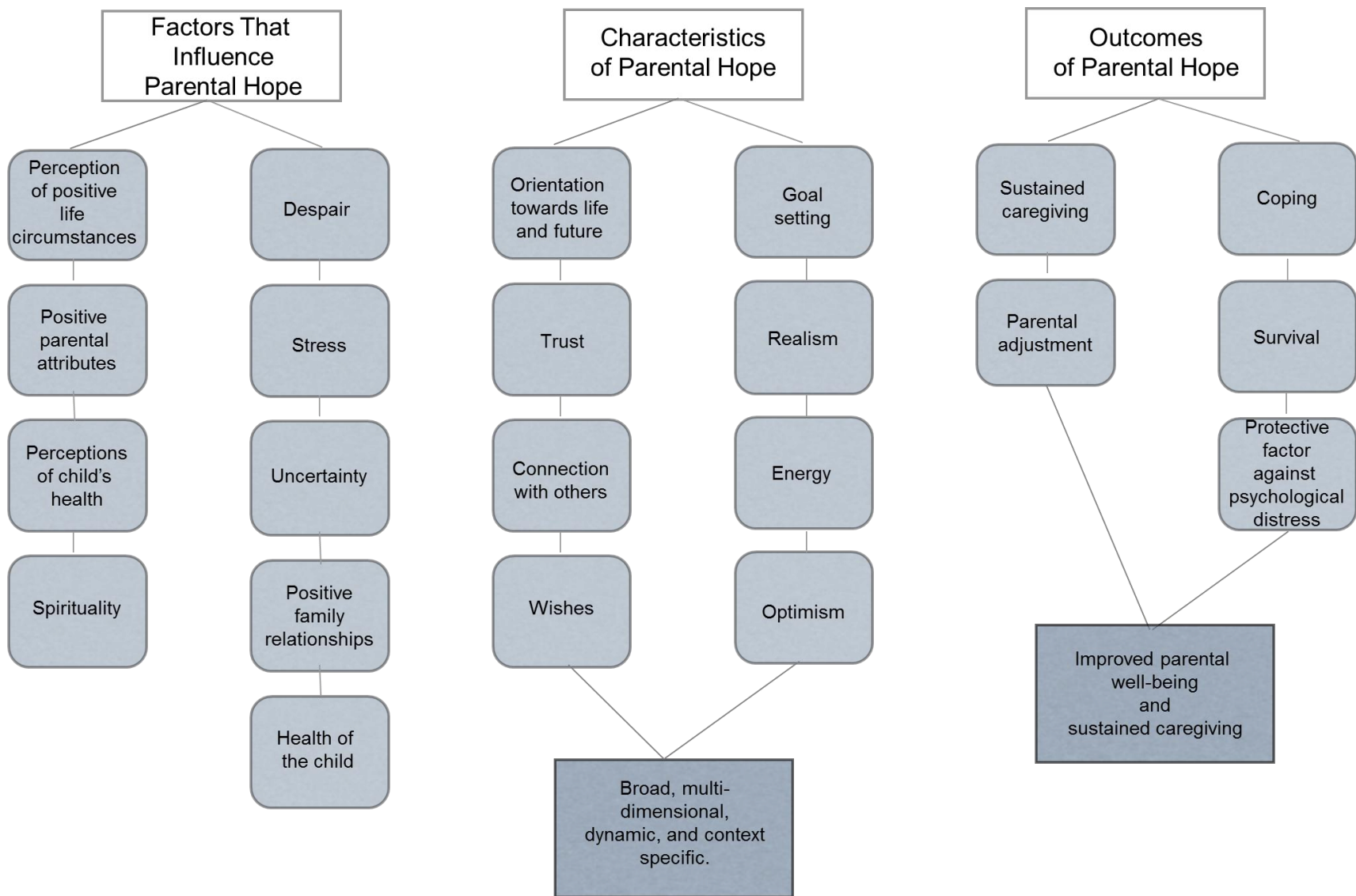


Figure 1.1 - A Synthesis of the Characteristics, Factors that Influence, and the Outcomes of Parental Hope

1.2.6.1 The meaning of hope for parents. Some parents saw hope as a survival tool (Kylma & Juvakka, 2007; Reder, & Serwint, 2009). Their hope acted as a buffer when stress was high (Horton & Wallander, 2001; Mednick, et al., 2007), and was life sustaining, positive, and useful for coping (De Graves & Aranda, 2008; Kylma & Juvakka, 2007; Reder, & Serwint, 2009). For these parental caregivers, hope was rooted in the caregiving experience (Kirpilani, et al., 2000; Samson et al., 2009; Thampanichawat, 2008). Many parents hoped for a cure and hoped that their child could return to a previous, ‘normal’, way of life (De Graves & Aranda, 2008; Samson, et al., 2009). Similarly, parents’ hope included the survival of their child (Reder & Serwint, 2009; Thampanachawat, 2008).

1.2.6.2 Factors that influence parental hope. The findings from some studies indicated a variety of factors that influenced hope. These factors included the perception of negative life circumstances, positive parental attributes, and perceptions of their child’s illness. Other factors that influenced hope included stress (Samson et al., 2009), uncertainty (Aranda & DeGraves, 2008), the health of the child (Thampanichawat, 2007; Venning Elliott, Whitford and Honor, 2007), and positive family relationships (Samson et al., 2009).

Stress and uncertainty resulting from a child’s diagnosis, or from critically ill newborns (Amendolia, 2010) created feelings of despair, but these conditions influenced parents’ hope (Kylma and Juvakka, 2007). Amendolia (2010) provided some insight into the relationship between hope and uncertainty and stress in her concept analysis relating to the hope of parents of critically ill newborns. She contended that hope becomes essential during this major stressful life event and “encompasses uncertainty, suffering, potential for loss, and a temptation to despair” (p. 143). Similarly, De Graves and Aranda (2008) succinctly stated, “uncertainty creates the possibility for hope; the lack of certainty of death keeps hope alive” (p. 299). As the perception

and understanding of the child's illness changed, the temptation to despair also changed, and hope for recovery was identified. As Samson et al (2009) concluded, "perception is the source of hope and gives it its colour and flavour" (p. 112).

Caregiving by parents also influenced hope (Kauser, Jevne, and Sobsey, 2003; Samson et al., 2009). As caregiving became focused, hope developed as an essential aspect of that experience. The presence of these factors gave rise to more positive parenting and caring experiences, which in turn, influenced hope (Kauser, Jevne, & Sobsey, 2003).

Diagnoses, prognoses, and the complexity of the child's illness were also listed as factors that influenced parental hope (Thampanichawat, 2007; Venning Elliott, Whitford and Honnor, 2007). Some of the findings, however, indicated that the physician's ability to communicate information about the child's medical condition in a non-threatening, supportive manner helped to alleviate feelings of despair, and maximized parent's hope for their child's welfare. Another interesting finding revealed that parents' religion, and, or spirituality had a positive effect on their response to life threatening circumstances, and that this also influenced parents' hope (Samson et al., 2009). These authors suggested that when the revelations of the complexity and extent of a child's illness became overwhelming and unbearable, parents turned to their religious beliefs for help. Their belief in a greater power then influenced their hope for a cure for their child.

The above-mentioned studies included factors that influenced hope. These factors had a profound effect on enabling parents to provide care for their children, and they appeared to be essential for the parents' well-being. The factors included the perception of negative life circumstances, positive parental attributes, perceptions of their child's illness, stress, uncertainty,

the health of their child, and positive family relationships. This review also revealed that while these factors were presented in some of the studies, they did not appear in all of them. In addition, the identified factors that gave rise to hope were broad, diverse, complex, unique, and appeared to depend on the specific population identified. While the factors were numerous and included stress, uncertainty and despair, for example, not all the authors provided operational or conceptual definitions. Thus, these factors were not well defined and their connection to hope was not clearly delineated. Consequently, it remains a challenge to articulate clearly those factors that influence hope across populations.

1.2.6.3 The outcomes of parental hope. Parents involved in the reviewed studies described many outcomes of hope. Several common themes including sustained parental caregiving, parental adjustment and coping, and psychological distress were found in the descriptions of the outcomes of parental hope. Many studies identified hope as an important resource for parents who were supported and sustained in their caregiving. Specifically, the grounded theory study conducted by Thampanichawat (2008) demonstrated that hope motivated Thai family members to continue providing care for their children with HIV. Parents of children with spina bifida found hope to be critical to their care-giving abilities (Kirpilani et al., 2000). Similarly, findings established through a phenomenological study involving 9 mothers of children with cancer and three health care workers demonstrated that hope, along with faith and positive thinking, provided strength during trying times, and helped them to continue on in their journey (Fletcher, Schneider, & Harry, 2010). In addition, Larson (1998) used a case study methodology to investigate the meaning of childhood disability for six Mexican-origin mothers of children with various, severe disabilities. She concluded that “sustaining hope in the face of negative proclamations was tenuous but essential for these mothers in their maternal work” (p.

869). Patistea, Makrodimitri, and Panteli (2000) corroborated these findings in their interviews of 71 mothers and fathers of children diagnosed with leukemia, and concluded that hope was one of the most important factors associated with accepting the diagnosis of childhood cancer, with tolerating the multiplicity of related implications, and with continuing caregiving for their child and family.

Parental adjustment and coping with a new life and a challenging diagnosis were also positively influenced by hope. Parents of children with various disabilities found that hope assisted them in finding solutions, providing a comfortable life for their child, and in accepting reality. Hope also helped these parents to reframe their lives, such that, it ultimately became a positive and strengthening process (Kausser, Jevne, & Sobsey, 2003). Parents who cared for children with chronic physical conditions and disruptive behaviours and who had high levels of hope, also demonstrated more effective adjustment and coping processes (Horton & Wallander, 2001). More specifically, hope helped parents of adolescents with cancer to cope with their situation, and helped them to endure challenging situations including death, as well as survival (Kylma & Juvakka, 2007). A sense of coping and survival was also established as two outcomes of hope. For example, in their phenomenological study, Bjork, Wiebe, and Hallstrom (2005) contended that 17 families of children who were diagnosed with cancer strove to feel hope in their experience of a broken life world and who were striving to survive. To overcome their fear and feelings of powerlessness, these parents sought to rely on hope to develop a positive focus. These authors concluded that in part, by relying on hope, the parents acquired knowledge, achieved control, and some semblance of a normal life. Similarly, Angstrom-Brannstrom, Norberg, Strandberg, Soderberg, and Dahlqvist (2010) conducted an exploratory qualitative research study involving nine parents of children undergoing treatment for cancer, and found that

the parents experienced moments of hope for their child's recovery and survival, and fluctuated between hope and despair.

In two of the studies, parents found that hope acted as a protection against psychological distress. For parents with children who had Type 1 diabetes, hope served as a protective factor against psychological distress, helped parents adapt to the initial crisis, and sustained their adaptation (Mednick, et al. 2007). The selected studies clearly suggested that the outcomes of parental hope had considerable positive influence on the wellness and caregiving abilities of parents who had children with chronic illnesses, in the adjustment of the life changing situations of their child, in the improvement of their caregiving abilities, and as protection against psychological distress. However, it is important to note that there is a lack of the definition of terms used including coping, psychological distress, and parental adjustment. In addition, hope, as a consequence, is measured as a 'state' suggesting that it is dynamic. In some studies, it is measured as a 'trait' which suggests it is static and never changing. Therefore, it is difficult to understand clearly the concepts that are being measured, as well as the relationships amongst these concepts. It is also difficult to compare findings based on differing conceptualizations of hope.

1.2.6.4 Descriptions and definitions of parental hope. Unfortunately, there is not enough evidence from the literature to support the conceptualization of a definition of hope. Amendolia (2010) referred to the characteristics of hope, generally, and in her description of a model case related to the critical attributes of parental hope, she included "goal-setting, future orientation, realism, energy, uncertainty, and optimism" (p. 142). However, these attributes were not defined and their connection to hope was not clearly articulated. Corroborating and extending these findings, Kylma and Juvakka (2007) described parental hope as "an orientation towards life and

the future, trust, connection with others, and wishes” (p. 266). Moreover, Kylma and Juvakka (2007) suggested that parental hope is broad and multidimensional. Unique findings were also related by Samson et al. (2009) who stated that hope was highly individualized, a dynamic quality, was context specific, and did not necessarily stand alone. They contended that hope was concrete and specific, but it was also spiritual and intangible towards the end of a child’s life. This information suggested that hope is broad, multidimensional, highly individualized, context specific, dynamic, and is characterized by goal setting, future orientation, and connection with others (De Graves & Aranda, 2008; Kylma & Juvakka, 2007; Salmon et al., 2012). Similarly, Kars et al. (2010) suggested that hope was dynamic in nature and was ever changing depending on the nature of the child’s health. These authors identified the dynamic nature of hope for parents and concluded that “hope ran from hope for a cure, to hope for stabilization, to hope for a slow course of deterioration, to hope for maintenance of communication, to hope for a short terminal phase, no suffering and a peaceful death” (p. 1006). Reder and Serwint (2009) identified common themes that emerged in bereaved parents and health care providers’ definitions of hope. These themes included associations with positive outcomes, future orientation, coping strategies, and relation to spirituality. Thus, our understanding of parental hope remains poorly developed. Although some descriptors are presented, hope is not clearly defined. Therefore, additional research is necessary because neither a conceptual, nor operational definition of parental hope is possible with such limited current knowledge. Such a definition is essential as it would provide a foundation for future research.

1.2.7 Summary of the Synthesized Findings

Overall, parents indicated that hope was vital, and they often hoped for survival and for a cure for their child. Parents of children with LLIs and LTIs were in a unique position in which

they had to address the difficult thought of outliving their child. Many studies reported that parental hope was centered on finding a cure (De Graves & Aranda, 2008; Reder & Serwint, 2009). This is significantly important as it emphasizes the contention that acknowledgement of the unique, parental experience is essential in order to understand hope clearly, and to assess and intervene effectively with parents by supporting their hope, their wellbeing, and caregiving abilities. Despite an attempt at clarification, and analysis, parental hope remains elusive and abstract. It seems that hope is unique, and it is dependent upon the life circumstance and the philosophical stance of the individual who hopes.

Although the literature related to the hope of parents is limited in quantity, and therefore, reduces the potential for drawing definitive conclusions, the findings are relevant and interesting. Most studies in this review suggest that the hope of parents is a multidimensional concept because it encompasses a variety of characteristics that appear to be central to their hope. However, for parental hope, all attributes are not equally, or completely represented in many of the reviewed studies, and parental hope as a multidimensional concept remains inadequately developed in this population.

1.2.8 Implications for Future Research

The paucity of research related to parental caregivers of children receiving treatment for childhood cancer, the various limitations identified in the available research on parental caregivers of children with chronic life limiting or life threatening illnesses, and the resulting gaps identified, highlight the need for additional research. This review demonstrates that hope is a dynamic, complex, and multidimensional construct, and it serves a multitude of purposes related to the health and well-being of parental caregivers and their caregiving capabilities. Thus, for these reasons, future studies should be undertaken to clarify the meaning of hope for parental

caregivers of children who are receiving treatment for childhood cancer. Specifically, such studies should seek to determine when hope is needed, how hope helps parents, and what factors facilitate or threaten hope. Future research should also include larger, diverse samples, longitudinal studies, and an emphasis on qualitative studies in order to capture the voices and experiences of parental caregivers. In addition, future studies should investigate how their findings can be optimally actualized in pediatric oncology nursing practice. Efforts should be made to investigate and identify interventions that promote, sustain, and maintain hope for this population in order to inform and guide effective, holistic, family centered care.

1.2.9 Conclusion

Hope is a complex, fundamental human experience. This review of the literature related to parental hope revealed that the hope of these parents is essential, and it is an important aspect of their daily lives as they cared for their children with a variety of chronic illnesses. Parental hope is influenced by a number of factors including the perception of negative life circumstances, positive parental attributes, perceptions of their child's illness, stress, uncertainty, the health of their child, and positive family relationships. The literature suggested that hope provides parents with the ability to sustain caregiving, and influences parental adjustment, coping, and psychological distress. Some of these relationships and concepts, however, are not clearly explained. The review also revealed that our understanding of parental hope is not fully developed. However, a synthesis of the findings from the studies demonstrated that parental hope is broad, multi-dimensional, dynamic, and context specific. Jevne (1991) contended that it is a conceptual challenge to identify the elusive, and intangible qualities of hope that are embedded in the experience of those who hope, and indeed, the literature related to parental hope does not definitively clarify their hope. Thus, it is of concern that the basic building block, the clear

elucidation of the concept of hope for parental caregivers has not been formulated. Without this clarification, theoretical derivation is not possible, and ultimately, it results in a significant gap in nursing knowledge, and in the ability to care adequately for this population. To continue the clarification of the hope of parents, new research must consider the utilization of clearly outlined methodologies using both qualitative and quantitative approaches to explicate and understand the narratives and the experiences of unique populations, and to contextualize hope within the social experience of parents who hope. In addition, conceptualizing hope within these parameters makes good sense as this would highlight and align the known antecedents, outcomes, attributes, and definitions of hope generally, and embed these elements specifically and uniquely within the lives of those who experience and depend upon hope.

Based on evidence found in the relevant literature, parental hope is not adequately defined, nor understood, and there are gaps in the information about known characteristics, and outcomes of hope. The continued focused study of hope, specific to parents' experiences, and the social context within which these parents find themselves can provide evidence that can be utilized to construct middle range theory specific to this population. Isolating and identifying more clearly those variables that are related to, support, and threaten parental hope through quantitative research is clearly needed. This would help to guide further research, and inform holistic and comprehensive family centered nursing care.

SECTION 2

METHODOLOGY

A GROUNDED THEORY STUDY OF PARENTAL CAREGIVERS WHO HAVE CHILDREN IN TREATMENT FOR CANCER: KEEPING HOPE POSSIBLE

A GROUNDED THEORY STUDY OF PARENTAL CAREGIVERS WHO HAVE CHILDREN IN TREATMENT FOR CANCER: KEEPING HOPE POSSIBLE

2.0 Relationship of Section 2 to the Dissertation

The second section is a presentation of the key elements related to the methodology that was originally proposed for this research study. In keeping with the initial proposal, it is written in the future tense, and it has been adapted from the format of a Saskatchewan Health Research Foundation (SHRF) New Investigator Establishment Grant Application (2011). In this section, an overview of the research plan is presented, and it includes the purpose and objectives of the study, the research approach (design, setting, sample, data collection, and analysis), ethical considerations, as well as a timeline. A supporting letter (Appendix B), a letter to the recruitment collaborators (Appendix C), a letter of introduction for parents (Appendix D), the consent form (Appendix E), demographic form (Appendix F), interview guide (Appendix G), guide for parents for keeping a hope journal (Appendix H), and the research brochure (Appendix I) are included in the appendices at the end of the dissertation.

2.1 Introduction

Many studies indicate that during the initial period following diagnosis of, and treatment (chemotherapy, radiation therapy, and surgical techniques) for childhood cancer, parents experience emotional distress. This period has been described as a period of considerable psychological adjustment (Pai, Greenly, Lewandowski, Drotar, Youngstrom, Peterson, 2007; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000). A broad base of psychosocial support for parents during the treatment period has been recommended (Pai, et al., 2007; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000). Given the well-defined importance of hope for family caregivers, understanding hope from the perspective of parents as informal caregivers for their children undergoing treatment is essential. This may facilitate improved parental health, and ultimately, may support parental caregiving abilities (Kirpilani et al., 2009; Larson, 1998) and thus, the health of their children (Eliott, 2005; Farran, Herth, & Popovich, 1995).

Researchers describe hope as a complex and dynamic human experience. Jevne (1991) contended that it is a conceptual challenge to identify the elusive and intangible qualities of hope that are embedded in the experience of those who hope. In addition, Nekolaichuk, Jevne, and Maguire (1999) suggested that “frameworks that mask personal experience seem to widen the gap between theory and clinical practice ...” (p. 592). In her concluding statement, Yates (1993) called for the reconceptualization of hope given the fact that many questions can still be raised about the hope experience of cancer patients and their families. Similarly, in their concluding remarks, Duggleby et al. (2010) stated “continuous building of knowledge in this area is essential if health care professionals are to provide support to family caregivers to foster their hope” (p. 156). Thus, a more focused exploration and understanding of the complex, subjective, and

dynamic nature of parental hope for those who have children undergoing cancer treatment is essential and can be gained only through additional, focused study.

2.2 Purpose and Objectives

Hence, the overall purpose of this qualitative constructivist grounded theory research study is to gain a clear understanding of the experience of hope for parents who care for their child who is receiving treatment for cancer. Specifically, the objectives are: (a) to gain an interpretive understanding of the hope experience and processes of hope for parents who have children who are undergoing treatment for cancer; (b) to describe and define parental hope and significant related concepts for parental caregivers of children undergoing treatment for cancer within their social context; and (c) to construct a substantive theory that is grounded in the experiences of parents who care for their child with cancer.

2.3 Research Questions

The guiding research questions for data collection and analysis are: (a) What does hope mean to parents who provide care for their children who have cancer?; (b) How do parents define hope?; (c) What are the social processes of hope?; and (d) How does hope influence the caregiving provided by parents of children who are receiving treatment for cancer?

2.4 Research Approach

A constructivist grounded theory approach will be used to address the study purpose and aims of this research study. The constructivist approach includes the following assumptions: Constructivism acknowledges multiple realities, co-creation of knowledge between the researcher and the participants, and it “aims toward interpretive understandings of subjects’ meanings” (Charmaz, 2000, p. 510). Thus, constructivist grounded theory provides three key benefits for studying hope. First, it focuses on actions and substantive processes embedded within significant

social contexts. Charmaz (2005) described processes as consisting of “unfolding temporal sequences that may have identifiable markers with clear beginnings and endings and benchmarks between. The temporal sequences are linked in a process and lead to change” (p. 10). The underpinnings of symbolic interactionism can significantly assist in studying and understanding the complexities of the personal and dynamic nature of parental hope. Second, the constructivist approach will permit an insider’s view and takes into account time, place, culture, and situation allowing for a rich construction and understanding of the experience of hope for parents within their social context (Charmaz, 2005). Benzein and Saveman (1998) suggested that a true understanding of hope as a fundamental human experience is gained only from sharing people’s narrated experiences of hope. Lastly, grounded theory is useful for investigating those phenomena about which little is known. As determined from the review of the literature, there is very little known about the hope of parents who have children undergoing treatment for cancer, and therefore, an inductive approach will be most beneficial.

2.4.1 Setting

This study will be carried out with the assistance of registered nurses, the social worker, and Dr. Mpofu at the Saskatoon Cancer Centre which is situated in the Saskatoon Health Region, Saskatoon, SK, Canada. Approximately 25 new cases of pediatric cancers are diagnosed and treated annually in Saskatoon (C. Mpofu, Pediatric Oncologist, Saskatoon Health Region, personal communication, March 10, 2011). Data collection will take place in the participant’s homes, or another convenient environment in which the participants feel comfortable.

2.4.2 Study Sample

The study sample will include those parents who are the primary caregivers for their children undergoing treatment for cancer. For the purposes of this study, a primary caregiver is

defined as that parent who more frequently accompanies the child with cancer to procedures, inpatient hospitalizations, and clinic appointments, and who most often manages day-to-day care of their child, and therefore, may have higher levels of direct exposure to potentially stressful illness events and experiences greater levels of distress and caregiver burden (Best, Streisand, Catania, & Kazak, 2001; Pai, Greenly, Lewandowski, Drotar, Youngstrom, Peterson, 2007).

2.4.3 The Inclusion Criteria

The inclusion criteria for the study are: Participants must be English speaking and freely able to provide informed consent. Additional inclusion criteria for this sample will be parents of any age who are male or female, are the primary care provider for their child aged zero to 12 years, with a diagnosis of cancer, and who are undergoing active treatment for their cancer within approximately 12 months since diagnosis, through the Saskatoon Cancer Centre. The Saskatoon Cancer Centre serves Saskatoon and Northern Saskatchewan residents, and therefore, participants from both rural and urban settings will be included. Parents will be excluded if they are not able to provide free and informed consent, or are non-English speaking as determined by the experienced and qualified recruitment collaborator.

Initially, participants will be purposively sampled based on their familiarity with, interest in, and willingness to reflect on and discuss their hope experience (Morse & Richards, 2002). In addition, key factors taken from the literature will provide guidance in initial purposive sampling and include levels of stress, time since diagnosis, and parental gender. During treatment, for example, parents are subjected to a number of disease-related events, uncertainty related to success of treatment, and worry about the consequences of treatment, all of which relate to higher levels of stress and threatened hope (Amendolia, 2010; Kylma & Juvakka, 2007; Norberg, Linblad, & Boman, 2005). The reviewed studies indicated that time since diagnosis, influenced

family functioning and parental psychological outcomes, with higher distress being noted from the time of diagnosis up to approximately 12 months after diagnosis (Pai et al., 2007). The literature also indicated that generally, mothers are the primary caregivers, and therefore, tend to experience more traumatic events related to their child's treatment and daily care giving (Norberg, Linblad, & Boman, 2005), distress, and feelings of family conflict (Best, Streisand, Catania, & Kazak, 2001; Pai et al., 2007).

Hence, initial purposive sampling strategies will be employed to obtain a range of participants from both genders, various lengths of time since diagnosis, and different levels of stress experiences. As the study progresses and the core category emerges, participants will then be specifically selected according to questions that arise from the data already obtained. According to Charmaz (2006) theoretical sampling helps to elaborate and refine emerging categories and is conducted "to develop the properties of your category(ies) until no new properties emerge" (p. 97). These sampling strategies will aid in accurately reflecting the participants' experiences and in providing a tool for understanding them (Charmaz, 2005). In two similar grounded theory studies found in the related literature, 20 interviews were conducted with 27 informal caregivers of children with HIV/AIDS (Thampanachawat, 2008), and another grounded theory study by Kars, Grydonck, Beishuizen, Meijer-van den Bergh, and van Delden (2010) included 57 interviews with 44 parents of children with incurable cancer. In addition, for grounded theory studies Creswell (2007) suggested a sample of 20-30. Morse (1994) contended that 30-50 interviews were required, and Charmaz (2006) contended that 25 interviews are sufficient for small studies. It is also suggested that more importantly, theoretical saturation be the guide to determining sampling size (Glaser, 1992; Stern, 2001). Theoretical saturation is achieved when data collection uncovers no new properties or theoretical insights about, and the

emerging grounded theory is full and complete and adequately describes the experiences of the participants (Charmaz, 2006). Overall, because multiple sources of data will be collected, and two to three interviews will be conducted, it is estimated that a sample size of approximately 25 participants will be required.

2.4.4 Data Collection Procedures

As suggested in the letter of support (Appendix B), Dr. C. Mpofu will assist with, and arrange for the collaborative efforts of the social worker and two registered nurses in identifying potential participants who meet the inclusion criteria for this study. Dr. Mpofu and I will meet with the collaborators initially, and in an ongoing manner throughout the data collection phase to ensure that appropriate instruction and guidance are provided, and that questions and comments are addressed in a timely manner. In addition, the collaborators will be provided with a letter of introduction that can be referred to as the study progresses (Appendix C). These collaborators will meet with, discuss, and provide a letter of introduction (Appendix D) to parents who are under the care of the Saskatoon Cancer Centre, Saskatoon Health Region, and who meet the inclusion criteria for the study to determine whether or not I can contact them with additional information regarding their participation. If they agree, the collaborator will provide me with the potential participant's contact information. I will then contact the parent to provide added explanation regarding their participation in the study, to arrange a suitable time for the initial in person interview, and to obtain written informed consent (Appendix E).

Data collection for the study will consist of a demographic form, two to three open ended research interviews with each participant, journal writing, and field notes which will be used to collect rich and detailed data.

2.4.4.1 Demographic form. The demographic form (Appendix F) will be filled out following written informed consent and will provide data regarding basic participant information that can be used to describe the sample.

2.4.4.2 Face-to-face initial interviews. Following the completion of the demographic form, face-to-face open-ended audio taped interviews will be conducted with the parent who is the primary caregiver of their child undergoing treatment for cancer. The interviews will take place in the participant's home, or another environment in which the participant is comfortable and which is private and quiet. Grounded theories can be developed through diverse kinds of data (Charmaz, 2006), and "interpretive qualitative methods mean entering research participants' worlds" (p. 15), and therefore, in-depth open ended interviews will be utilized to develop and understand each participant's interpretation of his or her experience. The interview guide presented in Appendix G provides a framework for the initial face-to-face interview with each participant. The questions provide a flexible beginning for the interview but they may not be posed in order, or at all, depending on the participant's responses. In addition, the interview guide may be developed further as theoretical development takes place. New areas of concern may need to be investigated through a variety of questions and some of the initial questions may no longer be suitable as the study progresses. The interview will utilize questions with an emphasis on symbolic interactionism, and thus, will focus on going "beneath the surface of ordinary conversation and examine earlier events, actions, views, and feelings afresh" (Charmaz, 2006, p. 26) with the result being a reconstruction of a reality. Charmaz (2006) contended that in depth interviewing suits grounded theory methods in that they are both "open ended yet directed, shaped yet emergent, and paced yet unrestricted" (p. 28).

2.4.4.3 Follow-up telephone interviews. A second, and potential third interview are planned with each participant and will take place by telephone. Telephone interviewing has proven to be successful and effective in obtaining rich, descriptive data that aid in understanding human experience (Sturges, & Hanrahan, 2004.). Additional benefits of telephone interviews include obtaining less inhibited disclosure and reduction of the effects of social desirability, more relaxed conversation, decreased cost, and the ability to access a wider geographical area (McCoyd & Kerson, 2006; Sweet, 2002). These interviews will be used to follow up with the participant after the first interview. Once the journal has been completed, any questions that arise will be addressed, any leads or hunches discovered in the data will be investigated. By utilizing a second interview two to three weeks following the first interview, I will be able to examine in more depth, parents' hope experiences, the related processes and concepts that may evolve and change over time. The third interview will be carried out if any clarification is required following the first two interviews, and for confirmation of the emerging grounded theory. All face to face and telephone interviews will be audio-taped and transcribed verbatim by an experienced research transcriptionist.

2.4.4.4 Journal writing. In constructivist grounded theory, interviewing is complemented by other forms of data collection such as journal writing (Charmaz, 2006). Each participant will be asked to keep a journal for approximately two weeks between the first and second interview. A diary will be supplied for each participant along with flexible guidelines to follow for the journaling activity (Appendix H). Once completed, the journal will be mailed back to me (a stamped and addressed envelope will be provided at the first interview), photocopied, and returned to each participant by mail.

2.4.4.5 Field notes. As suggested in grounded theory, field notes will be utilized throughout the research process to provide description of the participant's environment, processes occurring in their environment, and anything that the participant finds disconcerting (Charmaz, 2006). For example, observations of the participant's behavior during the interview will be used to extend the information that is gathered in the interview process that is not necessarily clear. Field notes will be created during, and following each interview to aid in the gathering of rich data, and will be transcribed and analyzed throughout the research process.

2.5 Data Analysis

All interviews, journal entries and field notes will be transcribed verbatim by an experienced transcriptionist. Transcripts will be checked by the researcher for accuracy and analyzed manually, followed by the use of ATLAS.ti software for organization, storage, and further data analysis. Interview transcripts, journal entries, memos, and field notes will then be analyzed concurrently with data collection through a process called constant comparative analysis (Charmaz, 2006). Constant comparative analysis is made up of concurrent data collection, coding, and analysis and as Charmaz (2006) highlights, it also involves the researcher's engagement. Coding of data is intended to conceptualize the data through analysis and by identifying patterns of events. In constructivist grounded theory, data are interpreted through an emergent conceptual analysis. "They seek to find a range of variation in their data and analyses and look for relationships between their emerging categories" (Charmaz, 2009, p. 139). The data collected from all methods must be compared in order to integrate and saturate fully, the meaning, and the concepts and categories of the emerging theory.

Charmaz (2006) describes three stages of coding including initial, focused, and theoretical coding.. "During initial coding we study fragments of data – words, lines, segments,

and incidents – closely for their analytic import” (Charmaz, 2006, p. 42). During this phase of coding, it is important to stay close to the data and to code the data as actions. During coding, Charmaz (2006) recommended the use of ‘action codes’ in order to remain close to the participant’s experience and to reflect language used by the participants. “Initial codes are provisional, comparative, and grounded in the data” (Charmaz, 2006, p. 48).

Focused coding “means using the most significant and/or frequent earlier codes to sift through large amounts of data” (Charmaz, 2006, p. 57). This type of coding assists in determining the adequacy of the initial codes and in the analysis of events, meanings and interactions. Coding is seen as an emergent process and provides deeper insight into subsequent incidents. At this stage, codes are developed into concepts, categories, and properties. Focused coding allows for identification of connections between a category and its sub-categories. Charmaz (2006) recommends using constant comparison to move across the data and to compare data to the codes and categories to develop and refine the focused codes.

Theoretical coding involves specifying the relationships between categories and concepts. Theoretical codes are integrative. They lend form to the focused codes collected and can add clarity, as long as the codes match the data and substantive analysis. At this stage, relationships between the identified categories of the phenomenon should become more abstract as they begin to take on characteristics of a theory. “These codes may help you tell an analytic story that has coherence” (Charmaz, 2006, p. 63). Thus, the focused codes are analyzed and organized into a substantive theory that will describe parental hope, relationships to significant concepts, and the context within which hope occurs. Analyzing and integrating memos and literature will aid in formulating a rigorous grounded theory.

In keeping with constructivist grounded theory through the process of data analysis, it will be important to ensure immersion in the data so as to embed the narrative of the participants in the final research outcome (Mills, Bonner, Francis, 2006b). To do so, I will seek meaning in the data by searching for, and questioning tacit meanings about values, beliefs, and ideologies (Charmaz, 2006). The assumption is that the interaction between the researcher and the participant “produces the data, and therefore, the meanings that the researcher observes and defines” (Charmaz, 1995, p. 35). Theoretical saturation will be achieved when no further properties or relationships between codes and categories are identified. At this point, a sense of closure will be established.

A reflective journal will also be kept which will enable ongoing theoretical sensitivity and will provide opportunities to conceptualize ideas about what is happening in the data. This process, called memoing (Charmaz, 2006; Glaser and Strauss, 1967), aids in recording ideas about the data in order to develop tentative connections, and to explore emerging relationships among the categories. It is one of the most important steps between data collection and the formulation of the grounded theory. Charmaz (2006) contended that memoing “prompts researchers to analyze their data and to develop their codes into categories early in the research process (p.188). Memoing will be used to sample theoretically as the study progresses. In addition, Charmaz (2006) recommends the use of memos to acknowledge the researcher’s voice and presence in co-authoring the shared experiences that are of importance to the participants. Memoing will be carried out by documenting any and all thoughts and ideas about the data, codes, and categories, in order to capture comparisons and connections discovered as data collection and analysis progress.

2.6 Factors Influencing the Study

The study will be influenced by, and limited to, the experiences of those participants who are willing and able to participate. This may exclude those who decline to participate such as parents who are under overwhelming stress, financial, or time constraints and who may, therefore, experience hope differently. In addition, the study will recruit participants from a large teaching facility in Western Canada, and therefore, demographic details such as culture, religious preference, and income level may be somewhat homogeneous. In addition, the study design follows constructivist assumptions including the reflexive engagement of the researcher. Therefore, the resulting grounded theory will be an interpretive portrayal of the hope experience of parents with children who are undergoing cancer treatment and will employ the researcher's interpretations as well as those of the participants. The theory will also be contextually placed in time, culture, place and situation and may not be transferable to other experiences and populations. There are also methodological issues associated with the use of qualitative research strategies such as grounded theory including premature closure, inability to define a core category or basic social process, and achieving less than rich and full description of the parent's experience of hope. To capture a well-rounded picture of parental hope, future research may need to focus specifically on the hope experience of other populations including those with varied cultures, fathers, and siblings.

2.7 Rigor

Rigor for this study will be established using Charmaz's (2006) criteria for grounded theory studies that include credibility, originality, resonance, and usefulness. These criteria will be implemented throughout the research process from beginning to end. Credibility will be established by collecting rich data from a multitude of sources and by maintaining sufficient

evidence, or an audit trail for others to evaluate the research process independently. Originality will be gained through the discovery of new knowledge and insights into parental hope, which has yet to be investigated fully. The substantive theory that is developed may assist in developing new procedures related to assessment and intervention to enhance parental health. The criteria of resonance will be developed throughout the research process by carefully following the procedures related to constructivist grounded theory data analysis, and through verification of interpretation with participants. Usefulness will relate to the development of knowledge that may aid in filling the current gap in the literature and in the current health care that is provided. In addition, this research project will provide direction for future research.

2.8 Ethical Issues

Ethical approval for this proposed research project will be sought through the Behavioral Research Ethics Board at the University of Saskatchewan, and operational approval through The Saskatoon Health Region prior to data collection and any contact with participants. A written informed consent will be obtained that will inform each participant of a number of considerations including the purpose and procedures related to the study, potential benefits and risks, the storage of data, confidentiality, and the right to withdraw. Data that are collected will be stored in a locked filing cabinet, only accessible to the committee members and me, and will be kept in a locked cabinet at the University of Saskatchewan for at least five years, in keeping with the University of Saskatchewan policy. I will conduct all interviews. As an experienced registered nurse, and research assistant, I am well versed in therapeutic communication, conducting research interviews, and have the ability to assess and monitor participant concerns and well-being during the interview process. Part of the interview time allotted will be utilized to debrief and if needed, I will call a support person indicated by the participant for further assistance.

2.9 Relevance and Benefits

It is important to note that the basic building block - the clear elucidation of the concept of hope for parental caregivers - has not yet been formulated, and this is a major concern. Without the conceptualization of parental hope, theoretical derivation is not possible, and ultimately, there will be a significant gap in knowledge, and in the ability to care adequately for this population. To advance nursing knowledge and practice in the area of hope, identifying and understanding hope for parents whose children are undergoing cancer treatment is necessary. New research must consider the utilization of clearly outlined methodologies, explicate and understand the narratives and the experiences of unique populations, and contextualize hope within the social experience of parents who hope. In addition, understanding hope within these parameters makes good sense as this would highlight and align the known antecedents, outcomes, attributes, and definitions of hope generally, and embed these elements specifically and uniquely within the lives of those parents who experience and depend upon hope. Hope is known to be a vital and essential life force for parental care givers and a deeper understanding can facilitate the development of theory based interventions to support parental hope and thus, parental health and care giving abilities.

2.10 Knowledge Translation

During the development of this research study and following its completion, information and findings will be shared with other health care professionals through presentations at provincial, national and international conferences. It is anticipated that three research manuscripts will be published in peer reviewed journals contributing to dissemination of the research findings. In addition, the results will be posted on the *Living With Hope* website to reach a varied audience and will also be shared with the participants of the study.

2.11 Establishment of Career in Saskatchewan

I have a rich background in pediatric nursing spanning a period of 20 years and varied experiences including clinical nursing in Canada and abroad, clinical teaching, and research. I have developed a deep interest in pediatric health and illness, particularly as it pertains not only to the client, but also to the family as a whole. Through my clinical experience and the knowledge that I have developed through course work towards my PhD studies, it has become apparent that parents who have children with chronic illnesses, such as cancer, are exposed to a number of overwhelming stressors beginning with diagnosis and continuing through their unique and personal journey related to their child's illness. However, there is a lack of research related to holistic and comprehensive family centered care that includes the science of hope, and as a result, health care providers do not have a base of knowledge to support comprehensive clinical practice. Currently, Saskatchewan has an undeveloped and underused pediatric palliative care program that strives to provide care that considers all aspects of child and family health. Through this proposed research project, I will develop a program of research that will aim to enhance the care that parents as informal caregivers for their children with cancer receive. Ultimately, findings from this and future related research will assist in developing supportive nursing care that will optimize parental health and will support pediatric care and health in Saskatchewan.

2.12 Research Environment

The proposed research project highlighted herein will be conducted under the guidance of my co-supervisors including Dr. Wendy Duggleby and Dr. Lorraine Holtslander. Dr. Duggleby is an advanced oncology registered nurse and an expert in the areas of qualitative research and the science of hope. Dr. Duggleby is a member of the faculty of nursing in the University of Alberta, and currently holds a Research Chair in Aging and Quality of Life. Dr. Holtslander is

also a certified hospice palliative care registered nurse and a faculty member in the College of Nursing, University of Saskatchewan. Dr. Holtslander's expertise in the areas of qualitative research, family nursing and palliative care will be a tremendous asset.

In addition, my PhD committee includes Dr. Chris Mpofu who is a pediatric oncologist at the Saskatoon Cancer Center, Saskatoon and has valuable knowledge related to pediatric oncology and the needs of families with whom he works. Dr. Shelley Spurr is a registered nurse and a faculty member in the College of Nursing, University of Saskatchewan. Dr. Spurr is a specialist in the area of pediatric nursing, and has published her work in a number of peer reviewed journals. Dr. Roanne Thomas from the College of Arts and Science, Department of Sociology has expert knowledge and a great deal of experience in qualitative research in the area of patient health and illness, specifically in relation to cancer. Dr. Karen Wright is a registered psychologist and registered nurse who has specialized in palliative care and the study of hope, and has numerous publications in these areas of research.

Together, this committee provides a strong multidisciplinary team of professionals and researchers who offer a great deal of scholarly and practical knowledge, experience, and skill that will provide ongoing support in conducting qualitative research in the area of the hope of parents who are informal caregivers for their children who are undergoing treatment for cancer. In addition, many of the committee members will provide access to necessary research resources such as audio equipment, research facilities, and qualitative research software programs that will facilitate a rich and effective research environment. Dr. Mpofu will assist in arranging for the assistance of necessary nursing staff, medical colleagues, and the social worker in the Saskatoon Cancer Centre to assist with planned recruitment procedures.

2.13 Timeline

The expected course of research is expected to follow the suggested timeline developed in Table 2.1.

Table 2.1 Expected Timeline

	AUG 2011	SEP	OCT	NOV	DE C	JAN 2012	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP
Ethical Approval	√													
Recruitment Procedures	√√	√√ √√	√√ √√	√√ √√	√√ √√	√√ √√	√√ √√	√√ √√						
Data Collection and Analysis		√√ √√	√√ √√	√√ √√	√√ √√	√√ √√	√√ √√	√√ √√	√√ √√	√√ √√	√√ √√			
Writing Results												√√√√	√√ √√	
Completion of Dissertation														√√ √√
Knowledge Translation							√				√√			√

SECTION 3

MANUSCRIPT 1

**VIEWING THE ART AND SCIENCE OF PEDIATRIC NURSING THROUGH THE
LENS OF PARADIGMS: THE IMPACT ON HOPE FOR THE FUTURE**

VIEWING THE ART AND SCIENCE OF PEDIATRIC NURSING THROUGH THE LENS OF PARADIGMS: THE IMPACT ON HOPE FOR THE FUTURE

3.0 Relationship of Manuscript 1 to the Dissertation:

The manuscript presented in the following section is a critical review of the literature related to the hope experiences of parents who have children with a variety of life limiting and life threatening illnesses using selected paradigms. Parental hope was identified as a vital aspect of caregiving, coping, and stress management. Findings from the post-positivist, critical theory, and interpretive paradigms provided a developing, broad scope of evidence that contributed to a partial understanding of parental hope, but which also revealed that it is dynamic and multidimensional. Furthermore, the literature review revealed that additional research is required to investigate the hope of parents who have children in treatment for cancer in order to support family centred nursing care in pediatric oncology adequately. This manuscript was written in APA format (Sixth edition, 2009) to meet the guidelines for *the Journal for Specialists in Pediatric Nursing* in which it was published in July, 2012. A letter of permission from the *Journal for Specialists in Pediatric Nursing* to include this manuscript can be found in Appendix J at the end of this dissertation.

3.1 Abstract

Purpose. To Examine The Strengths And Limitations Of Common Research Paradigms Used In The Study Of The Hope Of Parents Who Have Children With A Variety Of Illnesses.

Conclusions. Research Findings On Parental Hope Extracted From Only One Paradigm Present Limitations To Related Knowledge Development. To Take Into Account The Contributions From Each Paradigm And To Allow For A Multi-Dimensional Understanding Of Parental Hope, A Multi-Paradigmatic Approach Is Needed.

Practice Implications. The Complementary Findings From Multiple Research Paradigms Can Lead To A Comprehensive Base Of Knowledge That Can Guide Future Research And Develop Effective, Family Centered Pediatric Nursing Care.

3.2 Introduction

Hope can be a simple emotional response to a variety of human experiences. It can also be, however, a complicated, abstract, and life sustaining entity that is difficult to comprehend. Consequently, its essence remains elusive. Specifically, the hope of parents of children with life limiting (LLI) and life threatening illnesses (LTI) has not been adequately examined, thus there are gaps in nursing knowledge that affect nursing care for this population. Addressing parental hope and the gaps in nursing knowledge seems overwhelming but, they are worthy of additional inspection. The resulting goal should be an integration of knowledge development in the science of hope and ultimately the advancement of the art of nursing in providing care for parental caregivers.

Nursing is both an art and a science, or as Barrett (2002) stated, “a scientific art” (p. 51). With such a unique, broadly encompassing foundation, knowledge of the discipline of nursing is complex, multi-faceted, and often abstract, but it consistently aims to improve the health of diverse populations. This paper is based upon the conceptualization of nursing as a practical science that serves, in part, as a tool to inform the art of nursing. The practical science of nursing suggests that scientific inquiry must yield findings that are relevant and applicable to nursing practice. Johnson (1991) stated that nursing “is science that deals with generalizations, and it is art that deals with the application of these generalizations in a particular situation” (p. 11). In the 21st century, debate about the kind of knowledge that is required to advance the discipline of nursing (Forbes, et al., 1999; Omery, Kasper, & Page, 1999; Reed, 2000) continues. During the past 50 years, nursing has developed into a polarized discipline with those who prescribe to an empiricist world view, those in opposition who support the interpretivist paradigm, and those who support the dominance of one mode of inquiry over the other. The debate, and especially the

opposition found in the historical and contemporary nursing literature regarding the development and constitution of nursing knowledge, may be reducing the potential for formulating comprehensive research findings from which to base nursing practice. The discipline of nursing sets out to discover and expand upon phenomena such as hope that are complex and require a multi-faceted approach taken from both social and biological sciences.

To address the current state of nursing knowledge in the area of parental hope, four paradigms of nursing research were examined. Specifically, the positivist, postpositivist, critical theory, and interpretive paradigms were used as a framework for examining the existing literature related to the hope of parental caregivers. This examination sought to determine the strengths and limitations of each paradigm in advancing the science of nursing knowledge and the art of nursing practice. Implications for future nursing research and practice are also discussed.

3.3 Paradigms and Parental Hope

3.3.1 Research Paradigms

Paradigms are described in various ways in the interdisciplinary literature. For example, in his classical work in the area of paradigms, Kuhn is critiqued in nursing literature for providing multiple descriptions of paradigms. He described them as both a disciplinary matrix, and as exemplars (Monti & Tingen, 1999). Weaver and Olson (2006) defined paradigms as “sets of philosophical underpinnings from which specific research approaches (e.g. qualitative or quantitative methods) flow” (p. 460). Guba (1990) defined a paradigm as “a basic set of beliefs that guide action” (p. 17). Denzin and Lincoln (2011) contended that paradigms are human constructions that define the worldview of the researcher and encompass ethics, epistemology, ontology, and methodology. Denzin and Lincoln’s (2011) description of paradigm is used in this

paper because of its comprehensive nature and its inclusion of epistemology, ontology, and methodology that provide a framework for the systematic and standardized use of research paradigms.

There are also numerous methods of classifying the paradigms utilized in nursing science. The examples cited in the nursing literature include Rawnsley's (2003) terms, human science 1, and human science 2, that correspond respectively to Fawcett and Garity's (2009) description of the naturalistic, and postpositivist paradigms. However, Fawcett and Garity (2009) added a third paradigm called the critical emancipatory paradigm. Denzin and Lincoln (2011) delineated four research paradigms and listed them as positivism, postpositivism, critical theory, and constructivism. Similarly, and for the purposes of this paper, Weaver and Olson's (2006) classification of four paradigms: positivist, postpositivist, critical theory, and interpretive were used. All paradigms, despite the seemingly endless barrage of nomenclature, seem to stem from either the empiricist, or the interpretive tradition.

Empiricism is often linked to positivism and to postpositivism. These paradigms are thought to subscribe to a reductionistic, objectivistic, and realistic approach to research (Cody, 1995; Monti & Tingen, 1999; Weaver & Olson, 2006). More specifically, Clark (1998) linked postpositivism to empiricism, but differentiated it from positivism contending that it was in itself a reaction to the inadequacies of positivism. Denzin and Lincoln (2011) supported this notion and contended that modern empiricism, postpositivism, is a modified version of positivism. The difference lies in the notion that positivists believe that there is a reality that can be studied and understood, but postpositivists argue that reality can only be approximated, not fully understood. In addition, unlike positivism, postpositivism can be extended to develop, support, and verify theory. The other paradigms described by Weaver and Olson (2006) include critical theory and

the interpretive paradigm. Cody (1995) stated that the “newer paradigm is seen as more relativistic, more holistic, more attentive to subjective phenomena, and more qualitative” (p. 144). Monti and Tinggen (1999) contended that qualitative research traditions support the acknowledgement of multiple realities, the importance of human experience and, thus, the emphasis is on subjectivity as opposed to empirical objectivity. Similarly, Fawcett and Garity (2009) stated that within the naturalistic paradigm “research participants’ descriptions of their own health-related experiences are central to research” (p. 94), emphasizing the subjective nature of their experience and their behavior.

To examine the use of each paradigm in the development of nursing research on parental hope, a literature search was undertaken using Medline, CINAHL, Web of Science, and PsychINFO in January 2011. Keywords, such as pediatric oncology, parents, parental caregiver, hope, life limiting illnesses and life threatening illnesses, and nursing were used. From 182 articles, 14 were chosen based on their relevance to this paper. All the studies were published in English, were extracted from peer-reviewed journals from 1990 – 2011, and dealt with the hope of parental caregivers of pediatric patients with LLIs, or LTIs. Of the 14 studies included in this review, six were qualitative and eight were quantitative. The methodologies utilized in these studies varied. The studies of a qualitative nature included the following designs: critical ethnography, phenomenology, case study, and grounded theory. The quantitative studies were correlational in design, save for one longitudinal study.

3.3.2 Parental Hope and Nursing Research

Although hope research in nursing has received a great deal of attention since the 1980s, the hope of informal caregivers including spouses, offspring, relatives and parents who have children with LLIs and LTIs such as cancer (Eapen & Revesz, 2003; Kylma & Juvakka, 2007),

HIV/AIDS (Thampanachiwat, 2008), and spina bifida (Kirpilani et al., 2000), have been studied to a lesser degree. Researchers have suggested that parents of children with LLIs and LTIs experienced distress, stress, anxiety, and altered coping (McGrath, 2000; Pai et al., 2007) that affected their overall health and caregiving abilities (Kars, Duijnste, Pool, van Delden, & Grypdonck, 2008; Svavarsdottir, 2005). These parents faced overwhelming difficulties, but out of their dilemma emerged hope, which for them was a helpful resource (Kausser, Jevne & Sobsey, 2003), a survival tool (Reder & Serwint, 2009), and was used to continue caregiving (Kirpilani, et al., 2000; Samson et al., 2009; Thampanichawat, 2008). Because parents identified hope as being important, gaining a clear understanding of parental hope in the context of caring for a child with a LLI, or LTI is imperative. Nurses have realized that hope plays an important role in how individuals manage their health, illness, and care giving experiences, but it appears that an adequate science of hope on which to base their practice is not yet available. In addition, in the current climate of controversy among researchers regarding their preferences and support for one method of knowledge generation over another, the development of an adequate science of hope seems difficult to achieve. This can result in the dismissal, or disregard for valuable nursing knowledge provided by other researchers with differing underlying philosophical perspectives.

3.4 A Critical Review of the Literature on the Hope of Parents Using Selected Paradigms

Cody (1995) stated that “the purpose of identifying and delineating paradigms is to organize the knowledge in a discipline into like and unlike schools of thought and to consider the differences” (p. 145). In order to delineate the contribution of the prominent modes of inquiry in the development of the study of parental hope within the discipline of nursing, the strengths and limitations of four paradigms were critically examined. Specifically, the ontology, epistemology, and the methodology of these paradigms were used to develop an understanding

of the current state of nursing knowledge in the area of parental hope of children with LLIs and LTIs, and to identify directions for future research.

3.4.1 Positivist and Postpositivist Paradigms

The original form of the positivist paradigm, logical positivism, is not widely used at this time and has largely been replaced by other paradigms in nursing research (Denzin & Lincoln, 2011; Gortner, 1993). Positivism is characterized by, and has been criticized for being associated with naïve realism, a ‘value-free’ view of scientific enquiry. For example, authors such as Denzin and Lincoln (2011) and Weaver and Olson (2006) described the impossibility of discovering absolute truth and of making observations that are value free. In addition, Denzin and Lincoln (2011) contended that this paradigm failed to address the theory and value laden nature of facts, the reciprocal nature of the researcher and those who were the object of research, and that this paradigm did not consider the context within which phenomena occurred. Other characteristics that define positivism include; hypothetico-deductive methods, formulating unilateral causal relationships or laws, and conducting statistical analysis (Fawcett & Garity, 2009). Weaver and Olson (2006) concluded that these tenets of positivism “may perpetuate technically oriented practice” (p. 464). Therefore, given the limitations of positivism and the movement towards post-positivist thinking, the following discussion was based upon the post-positivist paradigm.

Postpositivism stems from positivism, but it subscribes to a critical realist ontology, and modified dualist, or objectivist epistemology (Denzin & Lincoln, 2011). Like positivism, postpositivism still has a hypothetico-deductive component and uses statistical analysis. Weaver and Olson (2006) suggested that this paradigm is criticized because of its “reduction of people to parts and its dehumanization of them to scores and percentages for statistical analyses” (p. 464).

However, its strengths and contributions to modern nursing are also apparent. According to Gortner (1993) modern empiricism is well suited to clinical practice because of its potential. She specified that the “observables (mood state, vital signs, laboratory and radiographic findings) must be linked with the unobservables, those normal and abnormal physiological and psychological processes to suggest causal factors and thus treatment” (p. 482). Postpositivism seeks objective knowledge through replication, emphasis on concepts and variables that are well defined, and through precise measurements of the phenomena under study. Weaver and Olson (2006) suggested that the postpositivist paradigm is useful for the study of questions in nursing that require data collection and analyses taken from a representative sample, knowledge about specific interventions, and predictive theories. Similarly, Denzin and Lincoln (2011) suggested that positivism and postpositivism both aim to formulate causal explanations through experimental designs. Theories developed from the postpositivist paradigm are predictive in that they yield hypotheses for theory building and enable understanding through analyzing and describing phenomena of interest. Methodologies used within this paradigm include randomized controlled trials, quasi experiments, and qualitative methods such as grounded theory methodology (Glaser & Strauss, 1967; Strauss & Corbin, 1990, 1998).

Eight studies on the hope of parents of children with LLIs and LTIs utilized quantitative methodologies including cross sectional and one longitudinal design. Investigations sought to determine the relationship between hope and distress (Horton & Wallander, 2001), hope, stress, and maladjustment (Horton & Wallander, 2001; Kashdan et al., 2002), and parental hope and their child’s health-related quality of life (Kirpilani et al., 2000). Padencheri and Russell (2002) examined hope scores and numbers of challenging behaviours in their children and found that those parents who had children with multiple challenging behaviours had lower hope scores than

those parents with children with no, or minimal, challenging behaviours. In a cross sectional study, Venning, Elliott, Whittford and Honnor (2007) investigated the impact of a child's chronic illness on parents' and children's hopeful thinking. These authors found that parents' hope scores were significantly and directly related to self-efficacy and inversely related to depression. In addition, Mednick et al. (2007) found that mothers of children with type 1 diabetes who had high hope might have lower levels of anxiety.

The empirical findings from these studies suggested the importance of improving hope in parents to enhance coping (Horton & Wallander, 2001), family functioning (Kashdan et al., 2002), and the understanding and nurturing of hope in the long term care of children with spina bifida and other childhood disorders (Kirpilani et al., 2000). Some authors identified the need for hope-based interventions designed to teach the skills required to engage in hopeful thinking (Mednick et al., 2007; Venning et al., 2007).

These empirical studies on parental hope have positively influenced the science of nursing knowledge by describing relationships between hope and various aspects of parental health such as self-efficacy, anxiety, distress, care-giving abilities, family functioning, and stress. Knowledge gained from these research studies has the potential for advancing the art of nursing practice by guiding holistic nursing assessment and by identifying those at risk for hopelessness, and therefore, those who may require additional support. These studies may also guide future nursing research. For example, the hope studies conducted from the empirical paradigm have provided data from which to base hope interventions and guide future measurement of hope in other populations using the same previously tested hope measurement scales.

However, although both statistical and practical significance may be related to the findings of these hope studies, the limitations imposed by the realist ontology and objectivist

epistemology are apparent. An assessment of these studies, and the authors' suggestions for future research, often indicated the limitations related to the value placed on scores and the reduction of parental hope to relationships between two or more key variables of human health. For example, Horton and Wallander (2001) called for future research to determine specific conditions in which hope is an important factor, such as coping and problem solving. Similarly, Kashdan et al. (2002) concluded that the measurements used in their study were insensitive to ongoing life difficulties and the unique experiences of distinct populations. These authors called for future studies including variations in gender and in ethnic groups and suggested that the use of semi-structured interviews to identify stressful life events and strains would be beneficial. For example, quantitative empirical research does not adequately include the complex, socio-political environment that impacts human health because it relies heavily on objective measurement tools, a hallmark of empirical science, and because of its departure from nursing's objective of humanization of the health experience. Assigning a number to represent the degree of hope that a parent may or may not have perhaps may be a dehumanizing act, because it neglects those essential and holistic elements of the human experience.

The literature is replete with strengths of post positivist research, including its precision, credibility, objectivity, and the ability to corroborate research findings (Forbes et al., 1999; Gortner, 1993; Weaver & Olson, 2006). These are apparent in the literature related to parental hope and the resulting advancement of the science of nursing knowledge and the art of nursing practice. However, the apparent gaps in that knowledge stem not only from the limitations in the paradigm used for investigation, but also from the complex, abstract, and multi-dimensional nature of hope. Thus, the significant contribution of the empirical research findings can be substantiated, extended, and expanded by nursing research conducted using differing paradigms

that subscribe to varied ontological, epistemological, and methodological foundations. This may promote complementary knowledge development to address the complexity of hope and the discipline of nursing, thereby contributing to a better understanding of both the art and the science of nursing.

3.4.2 Critical Theory Paradigm

Critical theory is an extension of the interpretive paradigm, and includes grassroots and emancipatory movements. The etic perspective is integral to this paradigm. It is rooted in the philosophy of Habermas, Friere, and Marx (Browne, 2000; Kim, 1999; Kincheloe & McLaren, 2005). Denzin and Lincoln (2005) stated that this paradigm “in its many formulations, articulates an ontology based on historical realism, an epistemology that is transactional, and a methodology that is both dialogic and dialectical” (p. 187). That is, methodologically, critical theorists’ dialogical approach “seeks to eliminate false consciousness and rally participants around a common point of view” resulting in transformation (Guba, 1990, p. 24).

Cull-Wilby and Pepin (1987) contended that “as with other paradigms, the critical social paradigm needs to be pursued in nursing for its different insights and contribution to knowledge development” (p. 519). Specifically, critical social theory attempts to develop practical, pragmatic knowledge that is historically, culturally, and structurally situated and that is action oriented (Denzin & Lincoln, 2005). It addresses power relationships, context specific issues related to gender, social and political inequities, and enhances empowerment of marginalized participants and communities. In addition, Browne (2000) suggested that the emancipatory focus of critical social theory is congruently aligned with the social mandate of nursing. Specifically, Browne (2000) stated that:

. . . claims within nursing science about preferable forms of knowledge can be firmly grounded in a critical realist framework that presupposes the existence of power

structures that shape our social world and produce and reinforce individual and institutional inequities (p. 46)

However, Weaver and Olson (2006) claimed that critical social theory has been criticized for its focus on the collective rather than the individual. In addition, Fawcett and Garity (2009) contended that researchers must be aware of their own and other researchers' biases. This perspective is supported by Weaver and Olson (2006) who suggested that there is potential for power inequities among researchers.

One study was found on parental hope that was conducted within the critical theory paradigm. De Graves and Aranda (2008) utilized a critical ethnography to explore the experiences of families when a child with cancer relapses. These authors claimed that their research incorporated the theoretical tenets of critical inquiry "which relies on the reflexive relationship between the data, families and the principal investigator" (De Graves & Aranda, 2008, p. 294). Beyond its reflexive nature, critical ethnography is conventional ethnography with a political purpose and is rooted in the critical theory paradigm (Thomas, 1993). Kinchloe and McLaren (2005) contended that critical theory finds its method in critical ethnography. Ethnography, then, becomes the action related to critical theory. De Graves and Aranda's (2008) findings revealed that hope was an essential coping mechanism for families of children with childhood cancer after relapse, and that it occurred in the face of fear and uncertainty. The authors found that for these families, the hope for a cure assisted them in living through their experience and did not prevent them from understanding the potential severity of their child's illness (DeGraves & Aranda, 2008). De Graves and Aranda (2008) concluded that hope helped families live through their child's cancer and recognized the significance of the relationship between the health professional, the child, and the family as the means to supportive care. Furthermore, they emphasized the importance of maintaining hope for children with cancer as

well as their families when providing care and suggested that future research is required to develop integrative care models in which cancer-directed therapies and supportive care are key. They also identified the challenge in developing interventions that would assist families who live with the uncertainty of relapse to deal with fear and hope.

De Graves and Aranda's (2008) critical-theory-guided research, elicited rich, contextualized, subjective knowledge related to families of children with cancer who had experienced relapse. Elements from these findings have extended some of the findings related to parental hope that were identified within the postpositivist paradigm. For example, De Graves and Aranda (2008) provided an understanding of the meaning of the families' hope and fear in relation to receiving information, decision-making, and family life during relapse. These authors utilized the critical theory paradigm to forward ideas and to relate challenges for future hope intervention strategies. However, the 'action' component of this study is unclear. Typically, research in this area from a critical perspective would have the potential to uncover injustices and inequities related to the provision of ethically sound health care. The critical theory paradigm can be used to examine and improve nursing policies and procedures, enhance practice development by identifying the importance of hope for parental caregivers, describe its use and meaning, and empower both parents and nurses to use hope as a psychological resource to enhance health. In addition, the critique of social structures that compromise an individual's health, the generation of theory that is not biased by gender, class, and race are significant to nursing for developing and challenging different views and conditions that influence health (Forbes et al., 1999).

Critical theory as a paradigm of inquiry for the study of parental hope has much to offer the discipline of nursing but, to date, it seems to be largely absent. However, when used as the sole

lens from which to advance nursing knowledge, there may be some limitations. Critical theory is based on an ontology of historical realism. Truth is seen as independent and universal, and is shaped by gender, social, cultural, political, economic, and ethnic values that may not be shared by everyone (Weaver & Olson, 2006) and, thus, may preclude researchers from using this paradigm to serve the needs and address the issues of all participants. However, historical realism does address relations of power that shape social reality, a condition that is relevant and underlies nursing practice. Browne (2000) stated that underlying epistemological and ontological issues in critical social theory present limitations related to the knowledge needs of nursing science. Based on its realist ontology and on its epistemology, critical social theory may be limited in its ability to uncover differences in hope based on human variability and individual complexities. Both are of significant importance to the development of knowledge in the area of parental hope. In addition, Gortner (1993) stated that critical theory does not view physiological or biological aspects of human health and illness and, therefore, research from this paradigm is not of complete utility for nursing science. While there is value in drawing upon the tenets of critical and historical realism inherent in critical theory, a balance is needed in order to fulfill nursing's needs to understand hope from a subjective, individually based perspective that includes those biophysical determinants of health that are also important to the study of parental hope. Only one study utilized the critical theory paradigm in investigating parental hope, and there is a need to develop more knowledge from this paradigm to serve the needs of parents of children with LLIs and LTIs more justly and effectively.

3.4.3 Interpretive Paradigm

Monti and Tingen (1999) cited many reasons why the discipline of nursing adopted the interpretive paradigm. These refer to the difference between empirical studies and qualitative

studies, which extend beyond the ‘senses’ and derive knowledge from other sources and multiple realities; its congruence with the beliefs of nursing such as holism, individualism, and self-determination; and its inherent capacity to utilize various methodologies such as grounded theory and ethnography for generating theory and knowledge.

Ontologically, the interpretive paradigm suggests that reality is multidimensional. Each dimension is intertwined with others and is context specific. The primary goal of investigation is the search for human experience, and therefore, the emphasis errs on the side of subjectivity (Cody & Kenney, 2006). The emic perspective is central to this paradigm. Because of the complexity of humanity, multiple ways of knowing are valued and utilized for knowledge generation. Unlike the other paradigms discussed, the interpretive paradigm subscribes to a relativistic ontology that assumes reality is constructed inter-subjectively through meanings and understandings developed socially and experientially (Denzin & Lincoln, 2011).

Epistemologically, the interpretive paradigm considers “observations as subjective, value relative, or value mediated” (Weaver & Olson, 2006, p. 462). Fawcett and Garity (2009) contended that in the interpretive paradigm, reality cannot be separated from the researcher’s knowledge of that reality, and therefore, the researcher’s values are inherent in all phases of the research process. Like critical theory, truth is developed through dialogue. Thus, researchers working from within this paradigm seek to engage in an equal relationship with the research participants in order to create a shared understanding of experiences, meanings, and contexts (Fawcett & Garity, 2009). Methodologically, the interpretive paradigm seeks to generate theory inductively and the theory is then used to explain the data developed through methods such as grounded theory and phenomenology. The usefulness of this paradigm is found in its potential for developing theory when very little is known about a phenomenon of interest, and in doing so,

relationships between concepts can also be developed (Monti & Tingen, 1999). Although the interpretive paradigm leads to explanatory theory, this type of theory may not have strong predictive power due to the small number of participants sampled. However, in qualitative research, the goal is seldom prediction, but rather exploration and understanding of individuals' experiences and related subjective meanings. Other limitations of the interpretive paradigm may include the lack of acknowledgement of the physiological aspects, biological factors, and social structures related to human health and illness (Monti & Tingen, 1999; Weaver & Olson, 2006). In addition, potential problems related to insufficient data collection, lack of adherence to philosophical underpinnings, and sampling errors, for example, can render inadequate findings.

In the research literature on parental hope, five studies used the interpretive paradigm to study the personal subjective experience of hope. Samson et al. (2009) used a phenomenological study to examine the lived experience of hope among parents of children with Duchenne muscular dystrophy. For these parents, hope emerged uniquely and was dependent upon their appraisal of their child's illness. The authors concluded that hope "can help parents absorb the initial crisis, sustain their adaptation or prepare for the fatal outcome" (p. 103). Samson et al. (2009) stated that perceptions about illness may shape the nature of parental hope and indicated that particular attention needs to be paid to the nature of parental hope because it can provide an indication of coping and adjustment. Reder and Serwint (2009) addressed the concept of hope for parents and health care professionals during a child's serious illness by undertaking a qualitative content analysis of focus group data. These authors identified a number of themes in defining the concept of hope including: association with positive outcome, future oriented, coping strategies, relation to spirituality, and a concept innate to human nature. Significant findings also included the temporal nature of hope. Parents noted ways that their hope changed over the course of their

child's illness, the important balance needed between hope and prolonging their child's suffering, and their role as the 'bearers of hope'. Reder and Serwint (2009) provided important insight into parental hope and advised supporting hope for parents in a way that acknowledges its changing nature. Kauser et al. (2003) used a case study approach to identify the experiences of hope in families of children with various disabilities. They found that hope was transformational and a dynamic process that helped them to reframe their lives. Similarly, through an exploratory qualitative research approach, Kylma and Juvakka (2007) described the hope of parents of children with cancer as being central to life, broad, and multi-dimensional. They offered guidelines for nursing practice including the promotion of hope engendering factors, and the elimination of hope endangering factors. Lastly, Thampanachiwat (2008) used grounded theory methodology to explore how primary caregivers dealt with problems in caring for children with HIV infections. Maintaining hope was one of the major processes that helped these participants continue caregiving under stressful and often difficult circumstances.

All the studies using the interpretive paradigm were inductive, exploratory, and descriptive in nature. These studies offered unique personal, subjective descriptions of the experience of parents and their hope in various contexts. This has significant value for the discipline of nursing as it offers an insider's view of the participant's unique hope experience. Thus, the hope interventions that may be developed based on these findings would be specific to the needs of parents and would assist in further developing the art of pediatric nursing. Although the interpretive paradigm significantly contributes to the literature in the area of hope, it has limitations. Samson et al. (2009) and Thampanichawat (2008) indicated that their findings may not be transferable to other contexts, or populations, and recommended additional research to examine hope in relation to perception in other populations and situations. Specifically,

Thampanichawat (2008) emphasized the need for quantitative research to compare stressors, fears of loss, the burden of care, and social support of HIV infected parents with those of uninfected caregivers. Similarly, Reder and Serwint (2009), and Kylma and Juvakka (2007) presented their research findings as foundational work from which hope interventions may be developed along with educational support for health care workers to support their understanding of hope and to minimize tensions. Thus, the findings related to parental hope that were developed from the interpretive paradigm offer unique insight, as well as the possibility for extending the science of nursing through research and theory development, which in turn can inform the art of pediatric nursing practice. However, the body of knowledge related to parental hope was developed from a relativist ontology that subscribes to multiple realities grounded in the subjective experience of the participants. This may be a limitation because it is context and person specific. However, the interpretive paradigm seeks to discover the meaning attached to individual experiences and it is then up to the reader to determine whether, or not, the findings from one research study are applicable to a new and different situation or context (Guba & Lincoln, 1985). From an epistemological perspective, the findings are based on observations that are shared and dependent upon a co-created understanding that is developed through mutual interpretation, and the observations are value-laden. Some might contend that this biases the findings and constitutes a source of error. In addition, the interpretive construction and understanding of meanings are dynamic and constantly changing and, therefore, may be difficult to identify and utilize for both research and nursing practice. The pragmatic use of this kind of nursing knowledge in the practice setting can be problematic. Monti and Tingen (1999) asked what it meant for a person to be an open system and further questioned how one could evaluate or systematically assess a holistic being. The study of parental hope has certainly benefited from

the use of the interpretive paradigm, and it has extended the knowledge of nursing beyond that developed from the post positivist paradigm. However, when findings regarding parental hope are viewed singularly from this paradigm, only partial knowledge is gained.

3.5 Implications for the Art and Science of Pediatric Nursing: Hope for the Future

Pediatric nurses have an obligation to provide holistic and comprehensive, family-centered nursing care. Those parents who have children with life limiting and life threatening illnesses are exposed to conditions and experiences that create anxiety, family disorganization, and extreme stress. Parents caring for their children with illnesses such as HIV, spina bifida, Duchenne Muscular Dystrophy, and cancer, have indicated that hope is vital, and that it is an important resource that can act as a buffer against stressful circumstances and enhance their caregiving abilities (Kylma & Juvvakkka, 2007; Thampanichawat, 2008). Pediatric nurses are in an excellent position to support parents and to enhance their adjustment to their new and evolving circumstances through evidence based hope interventions and hope theory.

There is very little research evidence on which to base pediatric nursing care specific to parental hope. An examination of postpositivist, critical theory, and the interpretive paradigms indicated that eight studies were undertaken using the post positivist paradigm, only one from the critical theory paradigm, and five from the interpretive paradigm. These numbers alone, indicate that research from the critical theory paradigm is sparse and, therefore, it is very difficult to link knowledge and theory development to practice-relevant social and political actions aimed at improving health, health care and social conditions (Browne, 2000) for parents of children with LLIs and LTIs. In fact, DeGraves and Aranda (2008) clearly emphasized the need for articulating and developing hope-based interventions for this population. Conversely, eight studies on parental hope using the positivist paradigm were found in the literature. The empirical

findings from these studies have demonstrated that hope is tangible to parents, and that it is associated with factors such as the degree of disability and disruptive behaviours, as well as with concepts such as self-efficacy, and depression. The art of nursing, which can be founded on the empirical science of hope, includes the assessment of parental hope and the identification, development, and support of those human attributes such as self-efficacy and coping skills that relate directly to enhanced hope. However, hope is abstract and complex and, therefore, not entirely amenable to observation and measurement. There is clearly a multidimensional nature to hope that needs to be further developed and articulated (Dufault & Martocchio, 1985; Farran, Herth & Popovich, 1995). Through the understanding of parent's social processes and the meanings ascribed to their hope experiences, the interpretive paradigm can inform the art of pediatric nursing practice, and can allow for theoretical and conceptual understandings of parents' hope. In addition, clarity regarding those subjectively perceived social, cultural, historical, and spiritual influences on parental hope can be achieved. This clarification can increase the potential for successfully acknowledging parents' experiences and for supporting their hopeful practice through context specific interventions.

Relevant findings from each paradigm can contribute important information to nursing knowledge to advance research as well as the art of nursing practice. However, it is evident that much more research is required to accomplish this (Aranda and DeGraves, 2008; Kylma and Juvakka, 2007; Venning, Elliott, Whittford, and Honnor, 2007). The evaluations of the strengths and limitations of underlying paradigms in the extant literature on parental hope offer a unique perspective on required research and theory development. Evaluation of the contribution of knowledge from each research paradigm demonstrated that while each one has much to offer the study of parental hope, the particular ontological, epistemological, and methodological

orientation revealed gaps in the kind of knowledge that was advanced. Thus, it can be concluded that in conducting research in the area of parental hope, a predominant or single paradigm approach may disrupt the progress of the science of pediatric nursing, as well as the art of holistic nursing care. Based on the evidence presented in this paper, the science of nursing related to parental hope must be developed and advanced from a multi-paradigmatic approach. This would allow for a broad and comprehensive base of evidence from which to provide ethically sound, effective, and holistic nursing care that encompasses the complexities of both nursing and hope. A multi-paradigmatic approach to the study of hope in pediatric nursing is essential to scientific advancement (Cull-Wilby & Pepin, 1987; Gortner, 1983; Monti & Tingen, 1999). For the advancement of hope research, identification of the ontological, epistemological, and methodological strengths and limitations posed by each paradigm is necessary. In addition, careful and informed use of each paradigm is needed to advance the discipline's knowledge in order to promote an adequate science of hope research that can inform the artful practice of holistic, family centered pediatric nursing. A multi-paradigmatic approach allows for the co-existence of research findings on parental hope from the postpositivist, critical theory, and interpretive paradigms. Thus, the development of the art of pediatric nursing should be based on a broader and more comprehensive science of nursing. Specifically, a multi-paradigmatic approach also values the differences in hope research from a variety of paradigms and highlights the contribution of each (Monti & Tingen, 1992), broadens the scope of evidence contributed to nursing knowledge (Forbes et al., 1999), and allows for a multidimensional understanding of phenomena (Cull-Wilby & Pepin, 1987).

3.6 How Might This Information Affect Nursing Practice?

Hope is an essential aspect of human life, and understanding the hope of parents who care for their children with life limiting and life threatening diagnoses is difficult given the subjective, complex, and unique nature of their experiences. Although some studies on hope refer to the hope of parents, there is insufficient evidence on the topic to understand it fully and to guide pediatric nursing practice. Thus, additional research is sorely needed. The findings from this paper underscore the need for research to be undertaken from multiple paradigms in order to extend nursing knowledge in a comprehensive manner. An enhanced understanding of the proper uses, strengths, limitations, and contributions of each paradigm may assist nurses in selecting the research paradigm that best suits the research question. It has been demonstrated that each paradigm offers unique knowledge to the study of parental hope. Developing hope theory and interventions through observable measurement, understanding parent's subjective experiences related to hope, and critically evaluating unit specific policies and procedures related to hope interventions so as to challenge the status quo, are all important and worthy research objectives for advancing the art and science of the discipline of nursing. By discovering and utilizing relevant findings from all four paradigms used in existing hope research, nursing science can adequately inform nursing practice and, therefore, support pediatric nurses' ethical obligation to provide informed, compassionate, holistic, family centered nursing care.

SECTION 4

MANUSCRIPT 2

**A GROUNDED THEORY STUDY OF THE HOPE EXPERIENCE OF PARENTAL
CAREGIVERS WHO HAVE CHILDREN IN TREATMENT FOR CANCER: KEEPING
HOPE POSSIBLE**

**A GROUNDED THEORY STUDY OF THE HOPE EXPERIENCE OF PARENTAL
CAREGIVERS WHO HAVE CHILDREN IN TREATMENT FOR CANCER: KEEPING
HOPE POSSIBLE**

4.0 Relationship of Manuscript 2 to the Dissertation:

The second manuscript presented in the following section is a presentation of the findings of the study titled, *A Grounded Theory Study of the Hope Experience of Parental Caregivers Who Have Children in Treatment for Cancer: Keeping Hope Possible*. The manuscript describes the use of constructivist grounded theory to uncover the specific processes related to parents' hope experiences as they cared for their children receiving treatment for cancer. Through an analysis of parental narratives, parental hope is defined and a model depicting and describing the major basic social process of 'Keeping Hope Possible' and its sub processes are presented. The value of nurses' knowledge about how parents define their hope, and in understanding the related processes of parental hope are highlighted. This paper will be revised for submission and written in the publication style of APA, (Sixth Edition, 2009) to meet the author guidelines of the *Journal of Pediatric Oncology Nursing*.

4.1 Abstract

This qualitative grounded theory study explored parental hope experiences within the context of childhood cancer. Thirty-three open-ended interviews and 14 journals were collected from 16 participants, transcribed verbatim, and analyzed using Charmaz's (2006) constructivist grounded theory methods. The findings revealed that parents of children with cancer defined their hope as essential, strengthening, and as a guide that helped them to prepare for the worst and to hope for the best. Their main concern was "fearing the loss of hope" and was ameliorated by the basic social process of "keeping hope possible". To keep hope possible, parents accepted the realities of childhood cancer, established control, restructured their hope, and chose to think positively. These sub-processes of keeping hope possible were influenced by a number of factors including the assessment of their child's health, gaining knowledge and experience, connecting with others, being in the loop, and reaffirming their faith. The findings from this study provide unique information about the processes of parental hope, and will assist in guiding future research related to its assessment and support.

Keywords: Parents, Childhood Cancer, Hope, Grounded Theory, Qualitative Research

4.2 Introduction

Childhood cancer is rare. However, it remains the most common disease-related cause of death, and accounts for more deaths than asthma, diabetes, cystic fibrosis and AIDS combined, and is second only to injury-related deaths among Canadian children (Canadian Cancer Society, 2011). The five-year survival rates for childhood cancers have improved immensely in Canada from 71% in the 1980s, to about 82% in the early 2000s (Canadian Cancer Society, 2011). Among Canadian children, leukemia is the most common type of cancer diagnosed, with central nervous system tumours and lymphomas coming second and third, respectively. Approximately 850 children are diagnosed with cancer, and 135 children may die from childhood cancer every year (Canadian Cancer Society, 2011).

The diagnosis of childhood cancer results in a lengthy treatment phase that not only affects the child, but also their parents. The resulting anxiety, stress, and fear are frequently documented in the related literature (Angstrom-Brannstrom, et al., 2010; Eapen & Revesz, 2008; Fletcher, Scheider, & Harry, 2010). In addition, the new parental caregiving roles and responsibilities are associated with frequent appointments, repeated hospital admissions, and high intensity care at home. These factors place unforgiving demands on the well-being of parents during treatment (Pai, et al., 2007; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000). However, many researchers have suggested that hope provides relief from the enormous pressures parents experience when their child has cancer (Kylma & Juvakka, 2007; Reder & Serwint, 2009; De Graves & Aranda, 2008).

Research related to the hope of parents who have children in treatment for cancer has demonstrated that hope is essential, and may be linked to continuing to live everyday, and to enduring the challenges associated with childhood cancer (Kylma & Juvakka, 2007; Reder &

Serwint, 2009). Although many researchers have described parental hope as important, they have not explored the concept directly, nor described its processes and properties. It is, therefore, essential that the hope experience of parents caring for their children in treatment for cancer, be explored. In their metasynthesis about the hope of family members caring for a person with chronic illness such as cancer, Duggleby et al (2010) found that hope was important independent of age, relationship, or setting. Although, they included only one study that related to parents of children with a chronic illness, their definition of hope offers a starting point to search for different concepts and processes in the current study (Charmaz, 2006). Duggleby et al (2010) defined hope as “transitional dynamic possibilities within uncertainty” (p. 148).

4.3 Background

Several studies have indicated that hope was important for parents who have children with a variety of life limiting and life threatening illnesses such as HIV/AIDS (Thampanichawat, 2008), disabilities (Kashdan et al., 2002; Kauser, Jevne, & Sobsey, 2003; Larson, 1998; Lloyd & Hastings, 2009; Padencheri & Russell, 2002), diabetes (Mednick et al., 2007), advanced cancer (De Graves & Aranda, 2008; Kars et al., 2010), critical and chronic illnesses (Amendolia, 2010; Horton & Wallander, 2001; Reder & Serwint, 2009; Venning, Elliott, Whitford, & Honnor, 2007), and spina bifida (Kirpilani et al., 2000). Other studies about hope and parents of children with a variety of life limiting and life threatening illnesses suggested that the hope of parents was related to motivation (Kashdan et al., 2002), goal setting and future orientation (Amendolia, 2010), and that it was highly individualized and dynamic (Samson et al., 2009). These studies suggested that hope was strengthened by extended family members’ positive attitudes and practical help (Kauser et al., 2003), improved child health, having faith and parental resources. Some studies revealed that hope was threatened by professionals’ negative evaluation of the

child's health (Kausser, et al., 2003), pain, uncontrolled symptoms, and parental fatigue (Amendolia, 2010). However, hope was important and useful in optimistic caregiving, and was an important factor related to parental health, well-being, and coping (Eapen & Revesz, 2003; Larson, 2003). The literature revealed that parental hope was a survival tool (Reder, & Serwint, 2009), acted as a buffer when stress was high (Horton & Wallander, 2001; Mednick, et al., 2007), and was life sustaining, positive, and useful for coping (De Graves & Aranda, 2008; Reder, & Serwint, 2009). For some parental caregivers, hope was rooted in the caregiving experience (Kirpilani, et al., 2000; Samson et al., 2009; Thampanichawat, 2008). Many parents hoped for a cure that would return their child to a previous 'normal' way of life (De Graves & Aranda, 2008; Samson, et al., 2009), as well as the survival of their child (Reder & Serwint, 2009; Thampanachawat, 2008).

Three studies focused on the hope of parents during the treatment phase of childhood cancer, and they indicated that hope was very important to parents as they cared for their child (Kylma & Juvakka, 2007; Liu & Yeh, 2010; Salmon et al., 2012). In all three studies, the samples included parents of children who were in active treatment, in remission, and had completed treatment, or who were considered 'survivors' (Kylma & Juvakka, 2007; Liu & Yeh, 2010; Salmon et al., 2012). An exploratory descriptive study completed by Kylma and Juvakka (2007) included focused interviews with nine parents of adolescents with cancer, two of whom were in active treatment, and the remaining four adolescents were considered to be survivors. Parents considered hope to be central, and life sustaining, and it supported them through the challenges of childhood cancer. Their hope was associated with suffering and despair, and the central elements of parental hope included trust, and an orientation towards life and the future. Kylma and Juvakka (2007) found that a number of external factors threatened hope such as the

deterioration of their child's health, negative care, poor resources, and other people's negative reactions. The factors that engendered parental hope included good care, improving adolescent health, and faith. Similarly, Salmon's et al (2012) longitudinal, qualitative study included recorded consultations with 53 parents of children with acute lymphocytic leukemia (ALL) at one, six, and 12 months after diagnosis. They found that parents' hope was necessary in order to parent effectively when faced with despair, and their hope was focused on the short term. Parental hope was interpersonal, and built largely on their faith in the oncologist. Hope also had a positive psychological dimension that enabled parents to shorten the timeframe in which their hope materialized, and this took effort and time to learn.

A quantitative, descriptive correlational study reported by Liu and Yeh (2010) reported findings from 200 mothers of children who had cancer. In this study, 90 children were in treatment for cancer, 11 of whom had relapsed, 62 had recently been diagnosed, and 48 others had completed treatment. They suggested that mothers who reported low uncertainty and low distress had significantly higher levels of hope as measured by the Herth Hope Index and QOL, compared to three other subgroups of mothers.

As previously indicated, the studies undertaken to date focused widely on a number of different pediatric chronic illnesses, and there is very little research based specifically on parental hope during pediatric cancer treatment. There are gaps in the information about known antecedents, consequences, and outcomes of hope, and currently, there is no clear definition of parental hope for this population. Consequently, the hope experience of parents who have children undergoing treatment for cancer is not fully elucidated, nor is it thoroughly understood.

In addition, although a few studies focused on childhood cancer, they presented samples in which it was unclear if the child was undergoing treatment for cancer (DeGraves & Aranda,

2008; Eapen, Mabrouk & Bin-Othman, 2008; Eapen & Revesz, 2003). Other studies used mixed samples of childhood cancer survivors and children receiving active treatment (Kylma & Juvakka, 2007; Liu & Yeh, 2010; Salmon et al., 2012; Venning, et al., 2007), and two sampled those parents whose child had incurable cancer at the end of life phase (Kars et al., 2010; Reder & Serwint, 2009). This may be problematic because hope may be defined, conceptualized, and used differently by parents depending on where their child was in relation to the childhood cancer diagnosis (diagnosis, treatment, end-of-life, or survivorship). Of the studies that focused on parents of children in treatment for cancer, only a few set out to investigate parental hope (De Graves & Aranda, 2008; Kylma & Juvakka, 2007).

In the abovementioned studies, a number of different methodologies were used, thus it was difficult to compare and contrast the findings. Given parents' emphasis on the importance of hope as part of their wellbeing and caregiving activities, identifying and understanding hope as it relates to parental caregivers of children with cancer is necessary for informing and advancing our understanding of parental hope, and for offering direction and guidance for future research in pediatric oncology. The purpose of this study was to explore the hope experience of parents of children in treatment for cancer using Charmaz's (2006) constructivist grounded theory methodology. The specific objectives of this research study were: (a) to explore the meanings and processes of hope for parents who cared for their children with cancer; (b) to examine the relationships between the concepts that were identified as being important to parents who experienced hope; and (c) to develop a tentative, substantive theory based on the experiences of parents who had children who were being treated for childhood cancer.

4.4 Method

4.4.1 Design

Understanding how parents' hope experiences shape, and are shaped by their context and circumstances, is central to the aims of this study. This is congruent with a qualitative, constructivist grounded theory approach whose foundation is symbolic interactionism. A symbolic interactionist perspective emphasizes that people interact with others and within their own social world. Based on those interactions, they continually reflect upon, evaluate, and redefine their own actions, the actions of others, and the meanings of things that are important to them (Blumer, 1969). In this study, how the parents interpreted meanings and acted within their own social context were essential to understanding their hope experiences. In addition, there is a paucity of research related to parental hope, and therefore, grounded theory methodology is well suited to this study because it can be used to explore topics about which little is known (Charmaz, 2006).

4.4.2 Sample

After receiving ethical approval from an Institutional Ethical Review Board, and operational approval from a cancer centre in a small Western Canadian city that is associated with a tertiary care teaching hospital, purposive theoretical sampling (Charmaz, 2006) was carried out to reach saturation. Theoretical saturation was defined as theoretical completeness in which no new properties of the categories were identified (Charmaz, 2006). Initially, participants were purposively sampled based on their familiarity with, interest in, and willingness to reflect on and discuss their hope experience (Morse & Richards, 2002), and then they were theoretically sampled to elaborate and refine emerging categories (Charmaz, 2006). To recruit parents who cared for their children who were in treatment for cancer, the following inclusion criteria were

used by five recruitment collaborators (a pediatric oncologist, three registered nurses, and a social worker) to invite parents to participate: participants must be English speaking and freely able to provide informed consent; parents can be male, or female, of any age; are the primary care providers for their child from birth to 15 years of age who have a diagnosis of any childhood cancer, and who are undergoing active treatment for their cancer within approximately 12 months since diagnosis through the local cancer centre; and are from both rural and urban settings. Parents were excluded if they were not able to provide free and informed consent, or were non-English speaking. The recruitment collaborators contacted parents, in person, who met the inclusion criteria, and provided them with a study brochure inviting them to participate. If the parents were interested, informal, verbal consent along with their contact information were obtained by the recruitment collaborator. The researcher followed up in person, or with a telephone call to provide additional details about their participation and to obtain formal, informed, written consent and plans were made for the first interview.

4.4.3 Data Collection

Data collection took place over a 13-month period of time. Charmaz (2006) underlined the need to collect rich/thick data from a variety of sources, and defined rich data as “detailed, focused, and full” (p.14). The sources of data included a written demographic form, face-to-face, open-ended interviews, a journal completed by participants over a two-week period, the researcher’s field notes based on observations in the field, and memos. As is consistent with grounded theory, related literature was also used as another source of data in the late stages of data collection and analysis (Charmaz, 2006).

Face-to-face, open ended, audio-taped interviews typically took place in a private office in the cancer centre while the child was receiving treatment, and they ranged in duration from 28

minutes to 82 minutes. Participants were interviewed on two separate occasions, approximately two weeks apart, and three participants who were recognized as good informants who could expand on the analytical developments of the study, were interviewed a third time. An open-ended interview guide was used during the interviews, and was revised as data collection and analysis progressed in order to refine data collection by filling in gaps and expanding analysis. As data collection and analyses proceeded, more fathers, as well as rural and single parents were recruited to elaborate, refine, and fully develop emerging categories (Charmaz, 2006). The interview guide contained open-ended questions asking participants to describe their parental experiences since the time their child was diagnosed, to discuss their hope, define hope, and to describe what affects their hope as they cared for their child.

To gain greater insight into the day-to-day processes of parent's hope experiences, they were asked to write about their experiences in a journal over a two-week period, including what influenced their hope, how hope influenced their daily life, and to record general thoughts and feelings about their daily hope experiences. Field notes were documented after each interview in order to capture observations about the setting, interactions with health care workers and family members, and to take note of any behaviours, emotions, or non-verbal interactions that were otherwise not noted. Memos were also written by the primary researcher throughout data collection and analyses, and these provided a guide for constant comparative analysis, ultimately supporting theoretical sampling.

4.4.4 Data Analysis

Data analysis began once the first interview was conducted, and continued simultaneously with data collection throughout the research process. Interviews and journal submissions were transcribed verbatim by an experienced transcriptionist and then checked for accuracy by the

primary researcher. Charmaz’s (2006) constructivist grounded theory procedures were followed, including the use of three levels of coding (see Table 4.1).

Table 4.1 Keeping Hope Possible: An Illustration of the Coding Process

Quotations	Incidents	Categories	Concepts
“I think of my hope every day and yet I never know from day to day what hope will mean for me that day. It is just a journey in our lives. But, hope is always possible. I will never lose my hope”.	Changing hope keeps it possible	Changing hope to keep hope	Keeping hope possible
“You don’t realize how much hope there is in your life until you’re aware of it and looking for it and watching for it”.	Actively attending to hope		
“I don’t know how you could go through this without having some hope”.	Always keeping some hope	Always keeping hope	
“I will always have hope for my son”.			
“I always keep my hope. I change the focus of my hope depending on what’s going on. There’s always big hopes, but I also have more focused hope. It gets me through the stressful situation”.			

First, initial coding was completed line-by-line. This assisted in formulating categories and visualizing processes in the data, and it determined how to proceed with data collection. Initial

coding led to tentative ideas about the main concern, “fearing the loss of hope” and the basic social process, “keeping hope possible”, and indicated the transition to focused coding. Next, focused coding supported the adequacy of the initial codes and categories, elaborated those categories, and assisted in identifying relationships among the categories. This level of coding led to changes in the open-ended interview guide that focused on continued data collection and analysis. Theoretical coding was the third and final level of coding. The focused codes were analyzed and organized into a tentative theory that described parental hope, and specified its relationships with significant concepts and the context within which hope occurs. During this phase, a thorough literature search was completed, and relevant literature was integrated into the developing conceptual analysis to determine how and where the findings of this study fitted.

To establish scientific rigor for this study, Charmaz’s (2006) criteria for grounded theory studies were used, including credibility, originality, resonance, and usefulness. Credibility was established in this study by collecting rich data through multiple methods including interviews, journals, field notes, and memos, and through adherence to grounded theory processes and procedures such as purposive theoretical sampling and constant comparative analysis. An audit trail was created by keeping all data and a detailed description of the research process. Originality was addressed through staying close to the participants’ words by transcribing interviews and journals verbatim, and by using the participants’ authentic quotes to describe processes and sub processes. A final literature search was integrated into the findings to establish originality. Resonance and usefulness were ensured by reviewing and revising the findings with participants at second, and three third interviews. Finally, the findings were applied to the field of nursing emphasizing practice and research implications.

4.5 Results

4.5.1 The Sample

The sample for this study consisted of 16 parents of children who were in active treatment for a variety of childhood cancers (see Table 4.1). All parents who were approached, agreed to participate in the study. There were 12 mothers and four fathers who ranged in age from 21 to 48 years with a mean age of 36.6 years. There was a variation in their children's gender including seven females and 9 males whose ages ranged from three to 13 years, with a mean age of 7.2 years. The time from diagnosis to the first interview ranged from three weeks to 10 months.

Table 4.2 Participant Characteristics

Participant Characteristics (n-16)	
Age	Mean 36.6 years Range 21-48 years
Gender	Male 4 Female 12
Marital Status	Married 11 Single 3 Common-Law 2
Education	Post-Secondary 11 Secondary 5
Religious Affiliation	Roman Catholic 9 N/A 3 United 1 Protestant 1 Ukrainian Catholic 1 Anglican 1
Child's Age	Mean 7.2 years Range 3-13 years
Child's Gender	Male 9 Female 7
Child's Diagnosis	Acute Lymphoblastic Leukemia 7 Burkett's Lymphoma 2 Rhabdoid Tumor 2 Fibrillary Astrocytoma 1 Medulloblastoma 2 Hodgkin's Lymphoma 1 Brain Tumor 1
Treatment Received	Chemotherapy 10 Surgery/Chemotherapy/Radiation 6
Time Between Diagnosis and First Interview	Mean 3.7 months Range 3 weeks-10 months

Sixteen parents participated in a total of 33 interviews (14 participants interviewed twice, two participants interviewed once, three participants interviewed a third time), and 14 journals

were completed. The two participants who were not interviewed a second time, and who did not submit journals, did not respond to follow-up contact. Purposive sampling was continued until the main concern and the basic social process were identified in the data. Following this, theoretical sampling was employed to recruit participants who could inform the developing conceptual analysis, such as fathers, rural participants, and ethnically diverse parents. In addition, three participants who were perceived to be good informants were interviewed a third time because they were able to provide in depth insight to develop the properties of the concepts, and fill any gaps in the developing theory.

4.5.2 The Context

According to Charmaz (2006) the findings should always be contextually situated in time, place, and situation. The findings of this study were situated within the parents' experiences of having a child who was receiving treatment for cancer in a Western Canadian Cancer Centre. It is within this context that the parents journeyed through the portals of hope, sometimes fearing the loss of hope, but always keeping hope possible. These parental responses developed out of the uncertainty that resulted from the cyclical transitions associated with their roadmap, a plan of treatment for cancer, proposed by the oncologist. For the parents in this study, once their child was diagnosed with cancer, they found themselves bound to the proposed roadmap. While their cancer roadmap provided the comfort and knowledge of a plan, it also restricted their lives to the boundaries that it created. As a parent explained:

We have a roadmap so right now it is literally a daily schedule. I know what we are doing tomorrow and the next day and the next, but I can't plan a month from now because its new and I don't know enough. I don't have enough information about how that treatment protocol is going to look six months from now, or how he is going to react.

Although the parents were provided with a ‘plan’, a roadmap, it was their child’s unique reaction to treatment, both physically and emotionally, that truly dictated the progression of treatment and the resulting impact on the parent(s) and family.

The treatment for childhood cancer exposed parents and their families to “a roller coaster ride” that included many highs and lows, and were accompanied by feelings of shock, fear, uncertainty, lack of knowledge about and experience with childhood cancer, and seeing their child suffering. During the highs and lows, parents stated that there was a cyclical internal struggle in which dark, negative thoughts would “creep in” and “lurk in their minds”. During these lows, parents experienced anxiety, “depression”, fear, guilt, self-pity, and they would contemplate the “what ifs” in preparing themselves for the worst-case scenario. Parents’ negative thoughts included imagining their child’s death, their own response, and their child “going through hell and being really, really sick with treatments”, as one parent explained.

This roller coaster ride cycled between the highs and lows, through diagnoses and treatment phases of their child’s cancer. During this time, parents felt that life “had to be put on the shelf”, and everything revolved around the roadmap. As one parent said, “I’d like just one night for all of us where cancer isn’t the focus of everything”. It is within this context that the following findings were situated.

4.5.3 The Definition of Parental Hope

Parents who cared for their child during treatment for childhood cancer felt that their hope was essential. It sustained them, and allowed them to get through each day. One parent claimed, “hope allows us to come to terms with the roller coaster we were on, to get through the situation. If I didn’t have that hope, I wouldn’t have been able to be strong for (my son) and to help him feel safe”. The parents said that they always had hope, although their hope was sometimes easier,

or sometimes harder to find. Depending on their immediate circumstances, they restructured their hope, always “hoping for the best”. As one parent reflected:

Say, right now, I’m just hopeful that he will be cured and I hope that we will go through this journey and he’ll get well and go into remission, but if at any point throughout this journey it does change that it isn’t curable, that my hope would be changed to, okay, I just hope that in this journey with him, um, I just want him to be comfortable and I hope that that’s what it would be, so instead of it being, this would focus on that.

Typically, parental hope was focused on their own caregiving abilities (“I hope I have the strength to get him through this”), and hope for their child. One parent whose child was just potty trained wrote, “a small step, but hopeful (she) will continue her life full of big milestones”.

Parents defined their hope as powerful and it gave them strength. Hope acted as an inner guide that held them up in fearful times, when worried, stressed, or uncertain. As one parent maintained, “hope guides me when nothing is written in stone”. Specifically, hope provided parents with the strength to “be realistic” and prepared them for the worst-case scenario which ranged from the fear of their child as critical, lengthy illness, to the possible death of their child, and to visualize themselves moving through their child’s death. They described this as “preparing for the worst”. However, hope also guided them back to the positive thoughts they needed to “hope for the best”. For example, one parent said, “we have trained ourselves to hope for the best. If my thoughts are going South, I start hoping in my head for the best outcome and it kind of relaxes me”. Another parent explained:

I kind of, always prepare for the worst and hope for the best so that if the worst happens, I can deal with it ... I never want to be caught off guard. And, once I’ve gone to the dark part, the hope is easy. It’s almost like the hope is the sunrise, you know, once you’ve been through the really, really dark part and hope comes along, it seems like it outshines everything else and there’s no more shadows. I mean, I have moments of anxiety, I have the funeral half planned, I just had a moderately clear plan of what I would do if he died. But, it’s like I have to get rid of the poison, or the bad to focus on the hope.

Thus, parental hope is defined as an essential, powerful, deliberate, life sustaining, dynamic, cyclical process that is anchored in time, and is both calming and strengthening, and provides inner guidance through the challenging experience of preparing for the worst and hoping for the best. Parental hope helped parents to stay positive and to seek growth during their experience of caring for their child.

4.5.4 The Factors Influencing Parental Hope

Parents' hope was influenced by those factors that contributed to the movement between preparing for the worst and hoping for the best. These factors included their assessment of their child's health, gaining knowledge, connecting with others, being in the loop, and reaffirming faith. The most important influencing factor was the parents' assessment of their child's health, hope, and life. This is revealed in one parent's journal entry: "seeing (my son) so happy and healthy looking last Sunday has influenced my whole week. I am full of hope and positive energy". Another parent claimed, "her beauty outshines this ugly cancer. Her life is HOPE! Showing us all the good in a fearful situation". Gaining knowledge and experience with the roadmap was also important to parents: "During the low points, it challenged us, we found it hard to be hopeful until we knew more". Connecting with others also helped in keeping hope possible. Parents felt supported and comforted by family, friends, and health care providers. One parent stated, "the more people you have around you, surrounding you with hope, the easier it makes it for you to have hope". Being in the loop was also important to parents. One parent stated, "I get copies of everything, and I want to get all the results right away. I need to know what is going on, like don't leave me out of the loop – the good, or bad, or otherwise, don't leave me out of it". Lastly, reaffirming faith was important to most parents. As one parent stated, "I guess this reaffirms that I need to put my faith in the Lord and that helps me to be hopeful". One

parent who did not have a spiritual faith, stated that she put her faith in the competency of the oncologist and trusted that the health care workers knew what they were doing.

4.5.5 The Parent's Main Concern: Fearing the Loss of Hope

The parents in this study did not want to contemplate the loss of hope, and almost overwhelmingly maintained that they would never lose hope. However, the thought of losing hope was never far from their mind, and as one parent stated:

The fear of losing hope, I think about it, but I won't even allow myself to think of losing hope because once you allow yourself to go down that path, it's been developed, that thought process has been developed, so to me it's like, it's not even a consideration, not even an option. I never want to go through life thinking there's no hope. What's the point?

Two parents recalled times when they felt that they had lost hope. Both occurred at the time of diagnosis. One parent said, "I was jumping right into the worst scenario. I was afraid to go on, I was very emotional. I didn't think to have hope and it seemed like I'm in that tunnel and I'm going straight down". The other stated, "I don't think I had any hope or faith or I felt it was really wrong ... I think I was really hopeless. I don't like being in the bottom of a pit ... Even though I was around people, I felt very alone".

Most parents, however, maintained that they did not feel hopeless, but that during the low points, hope was harder to find, to see, and to grasp. These parents feared the complete loss of hope because it would be like giving up on their child, and giving up a future with their child and their family. Parents also indicated that they feared the loss of hope because that would leave them mired in dark and negative thoughts. They described this state as follows: "It feels incredibly painful, it feels helpless. It feels like you can't escape, like you are crippled". These parents resolved this main concern by keeping hope possible, within reach, and easier to find.

4.5.6 The Parent's Basic Social Process: Keeping Hope Possible

The parents dealt with their fear of losing hope by 'keeping hope possible'. This was the overall, basic social process central to all the data. Charmaz (2006) and Glaser and Strauss (1967) claimed that the basic social process united all the categories and explained much of the variation among the data. Keeping hope possible for these parents involved managing the challenging internal struggle that encompassed preparing for the worst and hoping for the best, and was situated in the treatment related ups and downs of childhood cancer. As one parent recalled, "I think of my hope every day and yet I never know from day to day what hope will mean for me that day. It is just a journey in our lives. But, hope is always possible. I will never lose my hope".

4.5.7 The Subprocesses of Keeping Hope Possible

To keep hope possible, parents purposefully progressed through the following four, interrelated subprocesses in a linear manner: accepting reality; establishing control; restructuring hope; and, purposive positive thinking. Depending on the many factors that influenced their hope and their ability to engage intentionally in keeping hope possible, each parent was at varying points in the process. Even though, at any given time, a parent may have proceeded through all the subprocesses, the negative appraisal of one, or all of the influencing factors, such as an unexpected set back, would begin the processes again, causing a back and forth movement between preparing for the worst and hoping for the best. The following section describes parents' hope experiences as defined by the related processes and subprocesses of accepting reality, establishing control, restructuring hope, and purposive positive thinking.

4.5.7.1 Accepting reality. As a subprocess of keeping hope possible, parents felt that they had to accept the diagnosis of childhood cancer and the resulting lengthy treatment protocol. As one parent explained:

I think that the key is that you first of all have to accept that my child has lymphoma, or leukemia, or whatever it is. We know that this is what it is, this is what is happening and we move forward. You can't get stuck. If you don't accept it, you can't have hope for what's going to happen in the future.

Parents described components of accepting reality as experiencing shock, questioning life, and engaging in reasoning. Experiencing shock occurred at the time of diagnosis, and it began the ups and downs of the roller coaster ride. "Right away you think the worst, but there was lots of hoping. Hoping it really wasn't cancer". At this time, parents recalled feeling shocked, fearful, anxious, and stressed. One parent stated, "it's life changing. Everything went out of my head, I just lost it. I was so scared". Another parent described uncertainty and loss of control when she stated:

It is like your whole world has stopped and you don't know where to go from there, and you don't know what's going to happen, and you don't know whether people are going to be okay or not, or how to fix it, or what to do about it.

Parents also described questioning life, their faith, the diagnosis, the fairness of their circumstances, and feeling a sense of self-pity in order to reach acceptance. One parent confided, "I went through quite a long period of time where I just kept thinking why me, why him, why us? Like what did we do so wrong that we have been dealt this?" The parents then described engaging in reasoning as revealed in the following quote:

I had my moments of that questioning, and then went, okay, it is what it is, he's been diagnosed, there's no, 'oh maybe someone made a mistake', it is what it is, it sucks in the big scheme of things, I don't understand who's pulling the strings, I don't know why an innocent six year old has to go through this, but then again, maybe it is happening to him to help us learn something.

4.5.7.2 Establishing control. Once the parents accepted reality, they were able to focus on their child and the journey ahead of them, establishing some control by assessing their circumstances, managing their caregiving responsibilities and modifying the timeframe within which they thought about the future, and preparing for the worst case scenario. Parents frequently assessed their circumstances by taking account of their own strength and emotional status, their child's status, their social support, their current knowledge and experience, and they also examined their own faith. Depending on their assessment, parents were then able to manage their caregiving responsibilities and modify the timeframe within which they thought about the future in order to avoid becoming overwhelmed. For example, a parent said:

Okay let's hope for today that he handles his chemo well, and we're able to go forth tomorrow and be hopeful that he handles that, and then he'll have the next drug tomorrow, and chemo again, and we'll see how he is feeling. So, I just go day by day and worry about today and whatever tomorrow brings, then that's what I'll deal with tomorrow, and be hopeful that it's something positive.

By continually modifying the timeframe within which parents looked forward into the future, they were able to re-establish some control in their lives and families. One parent explained, "It's a little kind of process and I just kind of take it one section of a day at a time. Sometimes it's one hour at a time. I can't do more than that". Once parents determined that they could manage their caregiving, and view their lives within a certain time frame, they had the strength and courage to begin preparing for the 'what ifs' and the 'worst case', using hope as their guide. As a parent explained:

Tomorrow is not promised to any of us, so I think at this point we just go day by day, and uh, hope for the best. I want to him to beat this, but at the same time it is a reality that might not happen. I just like to be prepared for the worst, so I think about all of the 'what ifs'. So I think that no matter what, hope helps you get through it.

Parents began to establish some control after accepting reality by assessing their current circumstances, and then accordingly, managing only what they could. They modified the time

frame in which they managed their caregiving by taking it one day at a time, or merely, one section of a day at a time.

4.5.7.3 Restructuring hope. After accepting reality and establishing some control, parents were able to restructure their hope to keep it possible, and to resolve their fear of losing hope. They did this by initially losing sight of hope, realizing the need for hope, and then changing hope. Parents often maintained that hope was harder to find, and losing sight of hope occurred when they were consumed by the internal struggle that tended to increase their negative thoughts. One parent stated, “it’s always there, some days are harder to see it than others”. However, parents realized the need for hope as they moved between “preparing for the worst” and “hoping for the best”. Losing sight of hope and realizing the need for hope seemed to be necessary steps in keeping hope possible because it motivated parents to ‘hope for the best’. This sentiment described their ability to restructure, and therefore, change their hope, thus making it easier to hope in any given situation, and to keep hope possible. It appeared that the essence of their hope stayed the same, but parents were able to change the outer aspects, the specific hopes, that they had. As one parent said, “the hope is that everything in the long run would turn out, or be better, or if that’s not the case, that at least the person’s in a better place and, and they are no longer suffering”. Another parent described her ability to restructure her specific hopes when she said, “in the beginning, my hopes were centred around the next few hours and they were focused. Whereas, now it’s more about the next year... I hope his energy levels get back up, that in a year this will be like it never happened, and his scans will still be clean”. One parent discussed the dynamic nature of her hope saying, “hope varies for me on a daily basis, almost ... Things can change in an instant and so does my hope”. Finally, one parent concluded, “life is very cyclical so for me, hope is very cyclical”.

4.5.7.4 Purposive positive thinking. After reframing their hope, parents described being able to find a positive side in their situation. For example, one parent confided, “your mind can focus on the negative but you need hope to focus on the positive. If you don’t have hope then there is no positive”.

Parents’ purposive positive thinking included making choices, training themselves, and changing their perspectives. The participants made a deliberate choice to think positively, rather than to become immersed in negative thoughts. One parent explained, “you just have to think on the positive side that people know what they are doing, and that all will go well”. Once the choice was made to think positively, parents then began training themselves to follow that pattern. As one parent explained, “I think as it’s gone along, we’ve kind of trained ourselves to just always think for the best and hope for the best”. Another parent reasoned:

You have to visualize the positive things and go it is what it is. The next three years of our lives, our social structure is focused on treatments. You have to find the positive in that. What helps me right now, is if I mentally rehearse a positive outcome in my head and then in my head it’s going to help me get to that positive outcome. Just keep thinking positive and watch my ability to catch myself and re-correct my thinking.

The parents who were able to make the choice and train themselves to think positively were then able to change their perspective and began to recognize and appreciate a new kind of normal. In turn, this new appreciation for themselves, their time with their child and family members, and a new kind of normal life further supported purposeful positive thinking. As one parent explained:

I took a lot of things for granted before ... now, I don’t just fly through it, you just take your time and appreciate the time you spend with people, or appreciate the things that you do. You don’t just take things for granted because life can change pretty quick.

Some parents were able to plan further into the future: “I can plan for the future ... To return to normal, our new normal, but with a, a newer appreciation of things. I use the hope of the future to carry us along”.

4.5.8 Summary of the Model: Keeping Hope Possible

The basic social process of keeping hope possible was important to all parents as they worked to resolve their main concern, fearing the loss of hope and is illustrated in Figure 4.1.

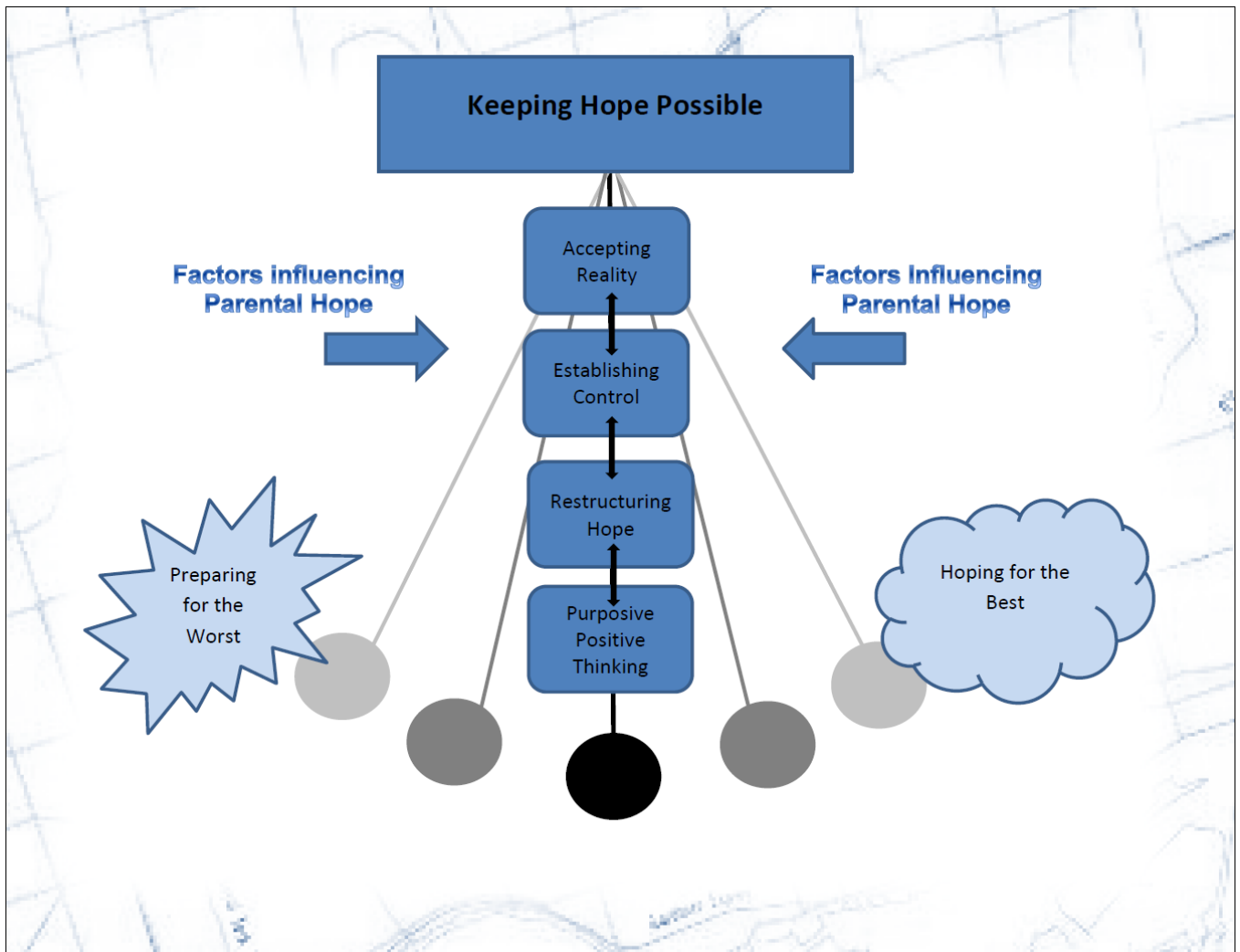


Figure 4.1 The Basic Social Process: Keeping Hope Possible

The model depicts an oscillating pendulum that signifies the sub processes in which all parents actively chose to engage, in order to keep hope possible. The mass of the pendulum represents

the interconnected subprocesses of keeping hope possible and included: accepting reality; establishing control; restructuring hope; and purposive positive thinking. The pendulum is anchored in the basic social process of keeping hope possible which is the pivot allowing the pendulum to oscillate between preparing for the worst and hoping for the best. Oscillation is generated back and forth by the factors that influence parental hope including: the parent's assessment of their child's health; gaining knowledge and experience; connecting with others; being in the loop; and reaffirming faith, as well as the mass of the pendulum itself, the subprocesses of keeping hope possible.

The motion of the pendulum is constant, and the movement through the subprocesses can be cyclical and dynamic as it is repeated over and over again as parents experience the ups and downs of treatment for their child's cancer. Even those who had difficulty in keeping hope possible, are captured in this model. For example, one parent who could be considered a contrast case, had difficulty in accepting the reality of her child's cancer diagnosis and the resulting life changes that occurred. This parent continued to work through the experience of shock and questioning her experience and had not yet proceeded to the next subprocess, establishing control.

Some parents willingly and deliberately polarized their thoughts towards preparing for the worst, while other parents found themselves there randomly, and involuntarily during quiet times, when they were tired, or when their child suffered a setback. The factors influencing parental hope, and the extent to which parents are able to engage actively in the subprocesses of keeping hope possible, determine the direction and the distance in which they move from one point to another between preparing for the worst and hoping for the best. Finally, the model is surrounded by a 'road map' that situates the basic social process of "Keeping Hope Possible"

within the context of treatment for childhood cancer. The road map depicts the various transitions related to treatment and the resulting uncertainty, stress, fear, and anxiety that parents experienced, and it provides the context within which the findings were interpreted and the developing theory was conceptualized.

4.6 Discussion

The findings of this study are presented within a tentative and developing substantive theory titled, 'Keeping Hope Possible' that describes how parents resolve their main concern - their 'fear of losing hope'. Hope is important for parents who care for their child who is receiving treatment for cancer, and it is associated with the ups and downs of childhood cancer, and with concepts such as uncertainty, and fear. These transitions and concepts are documented in the literature, but little is known about how parents define hope, and the processes of hope. This study reveals interesting and unique insights into the inlaid experience of 'preparing for the worst and hoping for the best', as well as the processes and subprocesses of keeping hope possible that are essential, prominent, and intertwined with parents' experiences of hope in the context of treatment for childhood cancer.

4.6.1 The Definition of Parental Hope

Parental hope was defined by analyzing parental hope experiences that are presented in this study, and by using their authentic descriptions and words in order to substantiate the researcher's interpretation. Their hope is an essential, powerful, deliberate, life sustaining, dynamic, cyclical process that is anchored in time, and is both calming and strengthening, thus providing inner guidance through the challenging experience of preparing for the worst and hoping for the best. This definition is unique in the existing literature related to the treatment phase of childhood cancer. However, some components of parental hope have been captured in

other studies. Kylma and Juvakka (2007) described the hope of parents who have adolescents with cancer, and included orientation to the future and life, trust, connection with others, and wishes. They contended that hope is broad and multi-dimensional. Similarly, other authors have indicated that hope is associated with positive outcomes, future orientation, coping strategies, and spirituality. They describe hope as being innate to human nature (Reder and Serwint, 2009), and is dynamic (Kauser et al., 2003; Sampson et al., 2009).

The parents in this study expressed fear of losing hope as their main concern. Larson's (1998) study of six Mexican mothers who cared for their children with various disabilities revealed that sustaining hope was essential, but often times tenuous, because the participants were battling their own fears and negative information. The fear of losing hope appears to be a process that has not been well investigated, and requires additional research.

In this study, parents resolved their main concern, the fear of losing hope, by keeping hope possible. This was the basic social process by which they purposefully maintained their hope as they moved through the unique sequence of preparing for the worst and hoping for the best. Contrary to this internal process of keeping hope possible, Kylma and Juvakka (2007) found that the hope of the parents in their study was affected by a number of external factors that either engendered hope (adolescent's health, economics, others, faith, and family pets), or endangered hope (adolescent's deteriorating health, negative aspects of care, poor parental resources, economic status, and others' negative reactions). In their study, it did not appear that there were any internal factors or characteristics related to the hope of parents. Other authors have found that hope is related to a variety of external influences such as faith in the oncologist (Salmon et al., 2012), the cognitive appraisal of their child's health (Kirpilani et al., 2000; Samson, et al., 2009; Venning et al., 2007), the severity of their child's illness (Padencheri & Russel, 2002),

receiving help with caregiving (Kauser et al., 2003; Mednick et al., 2007), and uncertainty (DeGraves & Aranda, 2008; Kars et al., 2010).

Like the current study, some studies referred to both internal and external resources that influenced parental hope. The study reported by Bjork, Wiebe, and Hallstrom (2005) revealed that families ‘strove to feel hope’ and had a positive focus to decrease their feelings of fear and powerlessness. This suggests an intentional, internal process similar to that of the parents in this study. Kauser et al. (2003) reported that parents’ hope was strengthened by both internal (belief systems, motivation, rationality) and external resources (family, friends).

Three studies described a process related to hope that is similar to the one found in this study. For example, Kars et al. (2010) interviewed 44 parents of 23 children with incurable cancer, and found that keeping hope alive was one factor related to parents’ internal struggle between a preserving frame of mind and one of letting go. These parents constructed some degree of uncertainty to retain hope because uncertainty provided the rationale for preserving hope. De Graves and Aranda (2008) found that 12 families whose children with cancer had relapsed, fluctuated between two states of reality: hoping for a cure, and contemplating death when confronted by the uncertainty of their child’s prognosis. These authors contended that parents’ hope was essential, but that it was profoundly influenced by uncertainty, and the pursuit of hope was similar to a protective mechanism. Reder and Serwint (2009) also found that 12 bereaved parents, and medical staff described the need to balance hope with accepting the reality of the prognosis. The two were in tension with one another, but could typically co-exist.

Although there appears to be some similar findings among the aforementioned studies, the processes by which parents hope, are not clearly explained. Thus, the related subprocesses of

keeping hope possible described in this study are unique and add insight into the processes of hope for parents of children in treatment for cancer.

4.6.2 Accepting Reality

Accepting reality was the key, initial subprocess in keeping hope possible. Through this first step, parents were able to begin to recognize and focus their hope by first experiencing shock, then questioning life, and finally, by engaging in reasoning. Although this information is presented in the literature relative to the diagnosis of childhood cancer, it has not been previously viewed as an important subprocess of parental hope in the context of treatment for childhood cancer. The literature related to the hope of parents with various chronic illnesses also revealed some similarities with the three aspects of this essential, initial subprocess of keeping hope possible.

Experiencing shock as a result of their child's cancer diagnosis was an important aspect of accepting reality, and it raised parents' initial reaction of fear, anxiety, and uncertainty that rendered them unable to grasp and focus their hope. Some studies in the extant literature relate similar experiences for parents who have children with other conditions. The key difference is that previous studies do not place this experience within the broader context of the processes of parental hope. For example, Bjork et al. (2005) found that the family's 'life world' fell apart, and they experienced fear, uncertainty, chaos, powerlessness, and loneliness after the diagnosis of acute lymphoblastic leukemia, and parents thought their child would die. Horton and Wallander (2001) stated that hope was a resilience factor, and Samson et al (2009) reported that it helped parents to absorb the initial crisis of the diagnosis of Duchenne's Muscular Dystrophy.

Parents also questioned the fairness of the diagnosis and the impending treatment phase. This step assisted parents in making sense of childhood cancer and the impact that it would have

on their lives, in thinking about their future, and in identifying those things that were important to hope for, such as their own strength, and their child's wellbeing. Accepting reality helped parents to move forward, beyond questioning the diagnosis of childhood cancer, and to accept that 'it is what it is'. Therefore, they could begin to hope for a positive outcome. Kauser et al. (2003) suggested that parental hope included an acceptance of the reality of their child's disabled condition. The unique nature of the processes found in this study, necessitate additional research to determine whether or not, accepting reality is a dimension of hope for parents in other situations in which uncertainty appears to be common.

4.6.3 Establishing Control

Establishing control was the second step in keeping hope possible, and parents were able to begin to gain some control over their lives, and to focus their hopes on the things that were important to them. Establishing control involved parental assessment of their child's health, managing their caregiving responsibilities and modifying the timeframe within which they thought about the future, and preparing for the worst. Descriptions of some of these aspects of this establishing control can be found in the literature related to parental hope, but they have not been conceptualized together as a part of establishing control.

The parents assessed their own strength, knowledge and experience, faith, social support, and their child's health status. Their assessment of their circumstances supported them in establishing some control in their new circumstances. Although how parents come to know about their own abilities and their child's health status are not clear in previous research, some, but not all of these elements can be found in the literature on parental hope. For example, previous research revealed that parents' hope was related to their child's deteriorating, or improving health status, parental resources, other people's reactions, and faith (Bjork et al., 2005; Kylma &

Juvakka, 2007), knowledge about cancer and treatment (Bjork et al., 2005), the cognitive appraisal of their child's illness (Samson et al., 2009), and a focus on the abilities instead of the disabilities of their child (Kauser et al., 2003).

Depending on their assessment, parents were able to manage their caregiving responsibilities effectively, and modified the timeframe within which they thought about the future. Managing and modifying the timeframe within which they managed their child's care enhanced parent's sense of control. This was an essential component of keeping hope possible. When parents attempted to contemplate the care of their child and family too far into the future, life became overwhelming, stressful, and they felt out of control, thus making it harder to keep hope possible. Previous research on the hope of parents presented similar results including readjusting the ultimate vision held for a child in order to manage the tension between fear and hope (Larson, 1998), and living in the moment to sustain hope. Dealing with life one day at a time also allowed parents to gain a sense of control (De Graves & Aranda, 2008).

Once parents assessed their circumstances, managed their caregiving and modified the timeframe in which they viewed the future, they were then able to do the important work of preparing for the worst. Hope sustained this activity, but at times, because of the dark and negative thoughts about their child's death and serious illness evoked at this time, hope was often harder to find. However, once parents completed this process, they felt they were in control, and keeping hope possible was easier. Similar to this very challenging and complex process, Kars et al. (2011) found that parents with children with incurable cancer experienced an awakening of hope, even when adopting a letting go attitude. De Graves and Aranda (2008) also described a challenging and emotional roller coaster ride for parents in which they fluctuated between states of awareness, hoping for survival, and facing the reality of death and preparing for loss.

The subprocess of establishing control provides new insight into the processes of hope for parents who have children in treatment for cancer. The aspects of establishing control and the relationship between this subprocess and the other three subprocesses of keeping hope possible were not previously reported in the existing literature. Future research is needed to explore this subprocess, and to elucidate the relationships among these subprocesses.

4.6.4 Restructuring Hope

The third related step in keeping hope possible was restructuring hope. This subprocess included losing sight of hope, realizing the need to hope, and changing hope. These components allowed parents to recognize the importance of hope. Although hope was initially hard to find, parents ultimately restructured their hope in order to focus on their child and the future, and to be able to ‘hope for the best’, in any given circumstance.

At times parents lost sight of hope. Because they were prepared for the worst-case scenario, and were just learning how to focus their hope, the inherent challenges and complexities of this phase placed hope out of sight, but it was still present. The restoring forces such as their child’s health, knowledge and experience, connecting with others, being in the loop, and reaffirming faith also negatively influenced parents’ need for hope and caused them to lose sight of their hope. Previous research have described similar aspects of hope including fading hope (Thampanichawat, 2008), dislodging of hopefulness (Larson, 2003), threatened hope (Kauser et al., 2003), and endangered hope (Kylma & Juvakka, 2007).

Realizing the need for hope was an important next step towards restructuring hope. Although parents had identified their hope, they had not yet internalized the need for hope. However, through establishing some control and having prepared for the worst, parents acknowledged their need for hope to help them seek out and focus on the positives in order to

replace their negative thoughts. The need for hope was described in the existing literature as being crucial and life sustaining (Kylma & Juvakka, 2007), essential (Kars et al., 2010), a necessity as part of the role of parenting (Reder & Serwint, 2009), and as essential in helping parents live through their child's cancer even with the awareness that a cure was not possible (De Graves & Aranda, 2008).

Losing sight of hope and realizing the need for hope were both necessary steps in keeping hope possible because they led parents towards changing hope, the final aspect of restructuring hope. Changing hope meant that parents restructured their hope in order to make it easier to find, and therefore, to keep it possible. Although the essence of their hope stayed the same, their specific hopes changed. For example, parents would change their hopes from specific to general, intense to mild, and from long term to short term, so that their hope could always be possible. A few authors have also described the dynamic nature of parental hope that changed from concrete and specific to spiritual in nature (Samson et al., 2009), expectational to desirable (Reder & Serwint, 2009), and in focus depending upon the progressive symptoms of incurable cancer (Kars, et al., 2011).

Although other studies described the dynamic nature of hope, the way in which parents consciously and actively 'keep hope possible' through the interconnected subprocesses of restructuring hope is unique to this research study. Future research could focus on this important aspect of parental hope to determine if this process exists in other phases of childhood cancer, such as survivorship, or other parent groups, and to investigate further, the relationship among realizing the need for hope, losing sight of hope, and changing hope.

4.6.5 Purposive Positive Thinking

Purposive positive thinking was the final subprocess in keeping hope possible for parents of children in treatment for cancer. Parents made a choice to think positively and to hope for the best. They had to train themselves to think positively, and this assisted them in changing their perspective.

Choosing positive thinking was the first step in purposive positive thinking. It appears to be the parents' conscious, cognitive manipulation of their situation that enabled them to think about the positives rather than getting mired in the negative aspects of their child's cancer. De Graves and Aranda (2008) described a similar phenomenon in which parents had the desire to remain positive and hopeful despite their challenging roller coaster of emotions related to relapse in childhood cancer. Other studies have described the association of positive thinking and hope, but not the deliberate choice to think positively. For example, being positive was crucial for parents (Salmon et al., 2012), their hope was engendered by a positive orientation to the future (Kylma & Juvakka, 2007), their parental hope was associated with positive effect (Lloyd & Hastings, 2009), and their positive focus may have led towards hope (Kauser et al., 2003).

After parents in this study chose to think positively, they began to train themselves to move away from the dark and negative thoughts and to find their hope. Typically parents used their own strength, positive thoughts of their child, and visualization of a better future in order to think positively. It was a learning process that occurred over time, after repeated exposure to the highs and lows of treatment for childhood cancer. This process has not been described in the existing literature on parental hope, and it, therefore, adds specific detail to the processes of hope for parental caregivers of children who are receiving treatment for childhood cancer.

The final aspect of purposive positive thinking is changing perspective. Following in a linear pattern, those parents who were successful in choosing, and training themselves to think positively, described the ability to keep hope possible, and the ongoing experience of changing perspective. They experienced a new kind of appreciation that came from their own personal growth including strength, courage, bravery, maturity, and selflessness, a commitment to be attentive to and appreciate the precious nature of their child's life and their family, improved parenting abilities, a renewed sense of spirituality, and enhanced relationships with others. Similarly, Liu and Yeh (2010) suggested that hope is central to the quality of life of parents. The findings in this study go beyond quality of life, to encompass an individualized, ongoing experience of self-betterment, improved relationships with others, and a reaffirmation of faith. Other parents expressed hope and profound personal growth that emerged from caring for a child with disabilities (Larson, 1998), and positive personal transformation, enhanced personal resources and increased tolerance related to parenting (Kauser et al., 2003). Purposive positive thinking is a unique finding, but it requires additional research focus to explore how it may be supported for parents and their families who are undergoing traumatic experiences associated with treatment for childhood cancer.

4.7 Factors Influencing the Study

The findings from the current study should be interpreted within the parameters of a number of considerations. First, this is an interpretive, constructivist study, and therefore, may be open to different interpretations. However, the findings will likely have theoretical reach. It is up to the reader to take from these findings, those aspects that may be of meaning and significance (Charmaz, 2006). Second, the sample for this study is somewhat homogeneous (predominantly Caucasian, Christian, female, urban) although purposive theoretical saturation was used to invite

as heterogeneous a sample as was possible. In addition, the parents in this study were invited to participate, and it may be assumed that those who chose to participate could have been more hopeful, or less hopeful than those who were not interested in participating, and therefore, they were more open to discussing their experiences about hope. This could have influenced the findings. Lastly, the sample was obtained from one treatment centre, which may limit the parents' collective perspective and resulting experiences.

4.8 Implications for Nursing Practice and Research

The developing constructivist grounded theory of keeping hope possible suggests that keeping hope possible is the intricate interaction among four distinct but interrelated subprocesses including accepting reality, establishing control, restructuring hope, and purposive positive thinking. This has direct implications for nursing practice. By using the definition of parental hope in this study as a guide, nurses may be able to better understand, assess, support, and identify those parents who are finding it harder to hope. Because parents oscillate between preparing for the worst and hoping for the best, informed and open communication can be used to support an ongoing and comprehensive assessment.

Many of the parents in this study reported that they found benefit to sharing their stories both in person and through their journaling. Because the parents' journeys were described as a 'roller coaster ride' that seemed to be turbulent and uncertain, nurses should encourage the story telling process. This may support parents in making sense of their own experience and also assist nurses in understanding, guiding, and supporting parents as they strive to keep their hope possible.

Knowing that parents prepare themselves for the worst case-scenario by visiting their child's death, and their own related reactions, can assist nurses in supporting parents in this very

challenging experience. Relating to parents what is known about other parents' hope experiences, providing timely, open, and honest communication about test results and plans, and supporting strategies to think positively, can all help parents to keep their hope possible by reducing uncertainty and helping them to maintain some sense of control.

Based on the findings in this research study, additional research is required to compare and contrast, and therefore, further develop the definition of hope for parent groups such as this one. There is no doubt additional research using samples of other parents who have children with a variety of life threatening and life limiting illnesses, and those who have children in different stages of the cancer experience, but with a similar sample from different treatment sites can add invaluable information to this area of study. Using different methodologies to explore and examine parental hope will add to the emerging theory presented in this study.

4.9 Conclusion

The presentation of the development of the tentative theory titled "Keeping Hope Possible", explains how parents deal with their main concern, fearing the loss of hope, through the basic social process of keeping hope possible. The process is complex and takes place within the context of childhood cancer. The findings of the study were supported by the existing literature, but the definition of parental hope and the subprocesses of keeping hope possible are unique and provide a substantial contribution to the knowledge base regarding parental hope. The findings provide both a foundation for future research, as well as a guide for nurses to provide holistic and comprehensive health care for parents of children in treatment for cancer.

SECTION 5

MANUSCRIPT 3

**PARENTAL NARRATIVES OF THEIR CARE GIVING EXPERIENCES WITH THEIR
CHILDREN WHO ARE IN TREATMENT FOR CANCER: RESTITUTION, CHAOS,
AND QUEST**

**PARENTAL NARRATIVES OF THEIR CARE GIVING EXPERIENCES WITH THEIR
CHILDREN WHO ARE IN TREATMENT FOR CANCER: RESTITUTION, CHAOS,
AND QUEST**

5.0 Relationship of Manuscript 3 to the Dissertation:

The third manuscript presented in section five is a planned, in-depth analysis of the data taken from a qualitative study. The manuscript is a description of the parental caregiving experiences related to their child who was undergoing treatment for cancer. Frank's (1995) three illness narrative types were used to categorize the data. Parents' stories reflected unique, varied, and complex caregiving experiences and discussions that were related to relevant literature, and highlighted the need for individualized and comprehensive nursing care. Suggestions for future research are provided. The manuscript will be revised for submission and written in APA (Sixth edition, 2009) format to meet the author guidelines for *Journal of Pediatric Nursing*.

5.1 Abstract

The purpose of this study was to develop an enhanced understanding of the complex, unique, and individualized experiences of parents who have children diagnosed with cancer. A narrative analysis of the data collected from a qualitative study about 16 parents who had children in active treatment for a variety of childhood cancers was undertaken. Thirty-three interviews and written entries from 14 journals were analyzed using Frank's three narrative typologies. Although all the narratives were presented in a chronological order from pre-diagnosis to the time that they were interviewed, the parents reported varying experiences while caring for their child during cancer treatment. The narrative analysis provides an insider's perspective, and therefore, a clearer understanding of these parents' individualized and complex experiences. Health care providers can use this information to provide holistic and individualized care for parents and to optimize their health and wellbeing.

Keywords: Childhood cancer, parents, caregivers, narrative analysis, pediatric oncology nursing

5.2 Introduction

Parents who care for their children in treatment for childhood cancer undergo tremendous stress (Angstrom, Norberg, Strandberg, Soderberg, & Dahlqvist, 2010), uncertainty (Grootenhuis & Last, 1997; Woodgate & Degner, 2003), and upheaval (Dockerty, Williams, McGee & Skegg, 2000; McGrath, 2001). The empirical literature examining parents' quality of life, coping, and adaptation during the various stages of treatment for their child's cancer reported varied reactions and experiences (Grootenhuis & Last, 1997; Long & Marlsand, 2011). In these studies, parents envisioned themselves as fighters, managing a battle that was thrust upon them. They focused on resurrecting the hope, strength, and courage required to face each test and procedure, day-by-day, and often hour-by-hour. Parents vigorously sought health for their child, and a life like the one they had 'before the cancer'. Some described their immersion in the chaos of a life with cancer from which they could not even begin to disengage. Often, they were too scared to hope for too much, and too tired to think too far ahead. To do so was overwhelming and full of uncertainty. Other parents were beginning, or hoping to emerge with 'new treasures and riches', a new normal with many gifts that had been reaped from their many challenges. They reported finding a new appreciation for life, enhanced parenting abilities, reaffirmation of their faith, and better relationships with their child, friends, and family. The commonality in all of these stories, was the parents' experience of active love, strength, and courage as they accompanied and cared for their child throughout the turbulent and challenging journey of cancer.

The personal stories of parents who care for their children with cancer can provide in-depth data. Polkinghorne (1988) contended that narratives play a key role in constituting meaning, helping to make sense of experiences, and in communicating meanings and experiences. To understand subjective illness experiences better, Frank (1995) provided a method of analyzing

told experiences of persons who were ill and were impacted by illness. Frank (2012) proposed that dialogical narrative analysis (DNA) “understands stories as artful representations of lives” (p.33), and that “stories reshape the past and imaginatively project the future” (p. 33). In his publication, *The Wounded Storyteller*, Frank (1995) revealed a typology of narratives including the restitution, chaos, and quest narratives (see Table 1).

Table 5.1 Frank’s (1995) Narrative Types

Narrative Type	Characteristics
1) Restitution	<ul style="list-style-type: none"> -Characterized by the plot, “yesterday I was healthy, today I am sick, but tomorrow I’ll be healthy again” (Frank, 1995, p. 75). -This narrative describes a belief in the restoration of health and portrays illness as transitory. It is the simplest narrative to hear and to tell.
2) Chaos	<ul style="list-style-type: none"> - The major plot of the chaos narrative is loss of control when the individual is “sucked into the undertow of illness” (Frank, 1995,p. 115). -Often the least heard story, as it can only be told once the individual is able to stand outside of the chaos. -The narrative is disjointed and without causal sequence or purpose.
3) Quest	<ul style="list-style-type: none"> - The quest narrative is identified by a narrative in which the individual takes control, and seeks “alternative ways of being ill” (Frank, 1995, p. 117). -Illness is seen as a journey from which something is to be gained.

Note. Adapted from Arthur Frank’s text, *The Wounded Storyteller. Body, Illness, and ethics* (1995).

He contended that in most illness narratives, all three types will be told, but one of the types will guide the narrative at any given time. A number of authors have examined the impact of chronic illness on a variety of populations such as those living with chronic fatigue syndrome/myalgic

encephalomyelitis (Whitehead, 2006), acute and chronic low back pain (Vroman, Warner, & Chamberlain, 2009), and women who had breast cancer (Thomas-MacLean, 2004) using Frank's narrative types. Frank's dialogical narrative analysis approach has been deemed useful as it has offered new insights into how illness is experienced (Thomas-MacLean, 2004; Whitehead, 2006) and constructive methods for quality improvement in health care (Vroman, Warner, & Chamberlain, 2009). This type of knowledge is valuable for informing and guiding clinical practice, clinical education, and future research.

The purpose of this paper is to report the findings of a planned in-depth analysis of data collected during a qualitative study on the hope experience of parents who have children in treatment for cancer. Data from face-to-face in depth interviews, and written journal entries from 16 parents were analyzed using Frank's (1995) method of dialogical narrative analysis. This analysis provides a unique exploration and explanation of parents' care giving experiences that are embedded in the context of treatment for childhood cancer, and thus adds to our understanding of their subjective perspective.

5.3 Background

Childhood cancer affects approximately 850 children and families per year in Canada (Canadian Cancer Society Steering Committee on Cancer Statistics, 2011). Treatment for most childhood cancers has advanced remarkably over the last 15-20 years, and has led to successful cure rates such that approximately 82% of children may be cured. However, the advancement in treatment regimes comes at the cost of a very long, often painful, stressful, and anxiety provoking treatment phase that may affect the quality of life for children and their families (El-Gamal & Long, 2010; Klasssen et al, 2011). For example, treatment for acute lymphocytic leukemia takes place through different phases including remission induction, consolidation, and

maintenance, and can last for two to three years (Canadian Cancer Society, 2012). The length of treatment and the severity of side effects have an impact on parents' state of health and well-being. The existing literature related to parents of children in treatment for cancer has focused largely on stress, coping, and adaptation in relation to child, family, and siblings, but findings related to parental experiences and reactions are diverse. Examining and understanding this diversity is crucial for both the storyteller, and for those who hear the stories because these stories illustrate the unique experiences and needs of the storyteller occurring within a specific social context. This allows health care providers who hear those stories to honour the story tellers, and therefore, to provide individualized, timely, and comprehensive care.

Numerous studies have identified factors related to the social context of parental caregivers that are important to parental health parameters such as socioeconomic status, gender, family, and marriage. For example, lower socioeconomic status was related to lower levels of parental psychological well-being (Dockerty, Williams, McGee, & Skegg, 2000; Smith, Baum, & Wing, 2005; Svavarsdottir, 2005). Employment factors such as job conflict with illness and being unemployed were both related to parental psychological distress (James et al., 2002; Sloper, 2000). Demographic variables including the child's mother as opposed to the father was related to higher levels of parental distress (Grootenhuis & Last, 1997; Sloper, 2000; Svavarsdottir, 2005). This may be because a mother's time spent on parenting and care giving tasks are rated as higher by mothers than by fathers (Brown, & Barbarin, 1996), and mothers were more likely to give up work outside the home (Koch, Harter, Jakob, & Siegrist, 1996).

Social support and family functioning are also important factors related to social context. Lower levels of perceived social support including spouses, relatives, friends, and formal care providers were related to psychological distress (Dockerty, Williams, McGee, & Skegg, 2000;

Han, 2003) and satisfaction with social relationships (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 2001; Sloper, 2000). Similarly, higher levels of perceived social support were associated with lower levels of anxiety (Dockerty et al., 2000; Sloper, 2000), and improved adjustment to their child's illness (Han, 2003).

A number of studies have demonstrated that parents who have a child in treatment for cancer experienced profound life changes (Nicholas et al., 2009; Tarr & Pickler, 1999) that included caring for their child as well as the whole family (Bjork et al., 2005; Woodgate & Degner, 2003). Some quantitative research studies suggested that there is a relationship between treatment for childhood cancer and lower levels of family functioning such as family conflict and poorer family relationships (Gerhardt et al., 2007; Morris et al., 1997; Robinson, et al., 2007). Other studies indicated that there was no difference in family functioning between parents of children with cancer and comparison groups (Brown et al., 2003; Sawyer et al., 2000; Streisand, et al., 2003). Qualitative research revealed similar findings, but also indicated that parents endured multiple stressors throughout treatment including managing treatment and side effect related hospitalizations and appointments with other life activities (Woodgate & Degner, 2003), and balancing the care of other children (McGrath et al., 2005; Patterson et al., 2004). Typically, the needs of the child with cancer tended to outweigh and overtake those of individual family members and the family as a whole (James et al., 2002, Norberg & Stenby, 2009). Overall, qualitative data indicated that many parents experienced positive family adaptation (Neil-Urban & Jones, 2002), while a few reported ongoing, challenging family issues (McGrath et al., 2005). In addition, quantitative studies revealed differing findings related to marital quality and parental quality of life when a child is in treatment for cancer. According to these findings, the quality of marital life can worsen (Hoekstra-Weebers et al., 1998; Kazak et al., 2001; Yeh, 2002), remain

unchanged (Chao et al., 2003; Lavee, & May-Dan, 2003), or improve in some subsets of study participants (Brody & Simmons, 2007; Dahlquist et al., 1996).

In addition to the above-mentioned factors related to parents' social context, caregiver characteristics and perceptions also weigh heavily on parental caregiver's health and well being during treatment for childhood cancer, and also show variability across parental experiences. Poorer caregiver psychological well-being was related to higher levels of uncertainty (Mu et al., 2001; Santacroce, 2002), increased perceived caregiver strain (Svavarsdottir, 2005), and a child being on active treatment versus off treatment (Moore, & Mosher, 1997; Yeh, 2002). Higher levels of anxiety were reported in parents who had children newly diagnosed with, or in treatment for cancer than those in off treatment and in remission (Yeh, 2002; Santacroce, 2002).

The aforementioned confounding factors found in the literature may be responsible for contradictory findings across studies. However, such findings may also be due, in part, to differences in parental perceptions of their caregiving experiences during their child's treatment for cancer. Thus, an enhanced understanding of parents' varied responses and experiences in caring for a child who is in treatment for cancer is warranted (Klassen et al., 2011).

The exploration of parents' stories of their care giving experiences may help in understanding their varied experiences as they face multiple stressors, and transitions over time. This knowledge can add a unique perspective to the current knowledgebase and may help to develop care that is individualized and family centered. Thus, the purpose of this study was to describe the varied caregiving experiences of parents who have children in treatment for cancer using Arthur Frank's (1995, 2010, 2012) dialogical narrative analysis and his three types of illness stories.

5.4 Method

5.4.1 Design

A planned in-depth analysis of the data collected for a qualitative study on the hope experience of parental caregivers who have children in treatment for cancer (Bally, unpublished) was completed. During the primary analysis of the data, thick, rich data relating to the parent's caregiving experiences emerged that resonated with the narrative typologies of "restitution, chaos, and quest" described by Arthur Frank (1995).

As Charmaz (2006) stated, "constructivism assumes the relativism of multiple social realities, recognizes the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understandings of the subject's meaning" (p. 510). She contended that all data are narrative reconstructions of experience, and this parallels, and is compatible with Frank's (1995) DNA in which he stated that "in the reciprocity of storytelling, the teller offers herself as a guide to the other's self-formation. The other's receipt of that guidance not only recognizes, but values the teller" (p. 18). He defined a narrative type as "the most general storyline that can be recognized underlying the plot and tensions of particular stories" (Frank, 1995, p. 75). Thus, with an emphasis on dialogue, Frank's (1995, 2010, 2012) three types of narratives including restitution, chaos, and quest were used to categorize and describe the variation in parental accounts of their care giving experiences for their child who was in treatment for cancer.

5.4.2 Sample

This sample used in this study consisted of parents who had children in active treatment for a variety of childhood cancers. Purposeful theoretical sampling (Charmaz, 2006) was used to invite parents who met the following inclusion criteria to participate: participants must be

English speaking and freely able to provide informed consent; parents can be male, or female, of any age; are the primary care providers for their child from birth to 15 years of age who have a diagnosis of any childhood cancer and who are undergoing active treatment for their cancer within approximately 12 months since diagnosis through the local cancer centre; and are from both rural and urban settings. Exclusion criteria included: the inability to provide free and informed consent; and non-English speaking. Recruitment collaborators contacted parents in person to invite them to participate, and if they agreed, the primary researcher contacted the participant in person, or by telephone to obtain formal, written consent, after providing more detail about the study.

5.4.3 Data Collection

Following ethical approval from an Institutional Ethical Review Board, and an operational approval from a cancer centre in a small Western Canadian city, data collection took place over 13 months. This included a demographic form, two to three open ended, in depth, face-to-face interviews, participant journals that were completed over a two week period, and researcher field notes and memos that were written throughout data collection and analysis. A flexible interview guide was used for the participant interviews and included open-ended questions that asked participants to describe their experiences at the time of their child's diagnosis up to the day of interview, and to discuss their hope experiences. Interviews were audio taped and transcribed verbatim. All but two of the 16 parents were interviewed twice because they could not be contacted for the second interview. Three participants were seen as good informants, and were interviewed a third time to present the data and ongoing analysis to them in order to seek their personal opinion and feedback. This procedure resulted in 33 interviews. Each interview lasted between 28-82 minutes. The hand written journals were completed by 14 parents, and they

included their daily experiences that occurred over a two-week period. Parents were asked to write about their thoughts and feelings related to their daily hope experiences. Two parents could not be reached to obtain their diaries.

5.4.4 Data Analysis

Data from face-to-face participant interviews and hand written participant journals were transcribed verbatim by an experienced transcriptionist, reviewed and checked for accuracy by the primary researcher, and entered into Atlas.ti computer software for organization and storage. Initially, data were analyzed using Charmaz's (2006) constructivist grounded theory procedures including coding the data via three stages (open, focused, and theoretical coding) and constant comparative analysis methods. During this time, important data related to the caregiving experience of parents of children in treatment for cancer emerged. An analysis was conducted using Arthur Frank's (2012) methods of dialogical narrative analysis. Frank (2010) claimed that, in agreement with Riessman (2008), analysis occurs through a flexible and intuitive process. During analysis, transcriptions were read several times, and particular attention was paid to individual differences in told experiences, the structure of the parents' stories, and the context within which parental caregiving took place. The data were analyzed and categorized according to Frank's (1995, 2010, 2012) three narrative types including restitution, chaos, and quest. That is, each of the participant interviews was initially summarized in three to four pages of handwritten notes to get a feel for the narrative. The raw data were then coded with specific attention to significant sentences, paragraphs relating to the narrative types, narratives about specific incidents, the structure of the interview, and ultimately each interview as a whole. Narratives were grouped into the three types of narratives set out by Frank (1995, 2010, 2012) and the groupings were documented. To ensure that trustworthiness and rigor of the study were

established, triangulation in which rich data were gathered through multiple sources including interviews, journals and field observations, and the contents of the first interview were checked during the second interview with each parent. Transparency was maintained at all times with full description of, and adherence to all stages of the research process. An audit trail was established through the confidential storage of all data and in keeping memos throughout the research process.

5.5 Findings

5.5.1 Participants

Participant demographic characteristics are presented in Table 5.2. Of the 16 parents who participated in this study, 12 were female and four were male. The mean age of the parents was 36.6 years (range, 21-48 years). The parents represented two ethnic backgrounds including Caucasian (71%) and First Nation (19%). Their children ranged in age from three to 13 years of age (mean, 7.2 years), and 44% were females and 56% were males. The children's diagnoses included acute lymphoblastic leukemia (ALL), medulloblastoma, and fibrillary astrocytoma. The length of time since the child's diagnosis up to the time of the first interview ranged from three weeks, to 10 months. All children were in active treatment for cancer at the time of the first interview.

Table 5.2 Participant Characteristics (n=16)

Participant Characteristics	
Age	Mean 36.6 years Range 21-48 years
Gender	Male 4 Female 12
Marital Status	Married 11 Single 3 Common-Law 2
Education	Post-Secondary 11 Secondary 5
Religious Affiliation	Roman Catholic 9 N/A 3 United 1 Protestant 1 Ukrainian Catholic 1 Anglican 1
Time Between Diagnosis and First Interview	Mean 3.7 months Range 3 weeks-10 months

Child's Characteristics	
Child's Age	Mean 7.2 years Range 3-13 years
Gender	Male 9 Female 7
Child's Diagnosis	Acute Lymphoblastic Leukemia 7 Burkett's Lymphoma 2 Rhabdoid Tumor 2 Fibrillary Astrocytoma 1 Medulloblastoma 2 Hodgkin's Lymphoma 1 Brain Tumor 1
Treatment Received	Chemotherapy 10 Surgery/Chemotherapy/Radiation 6

5.5.2 Narratives

The analysis indicated that each parent accounted for their experiences in a temporal sequence of events beginning with a period before diagnosis when the child exhibited suspicious and worrisome signs and symptoms, and continued through to the time of the interview.

Although events were told in chronological order, the telling of the story was deeply embedded in their child's illness experience, and all parents' narratives demonstrated a shifting dominance and movement among all three of Frank's (1995, 2010, 2012) types of narratives. This revealed the complexity of the parents' experiences, and the highly context specific nature of the narratives that depended largely on where the parents were in treatment for their child's cancer.

5.5.2.1 Restitution narratives. Restitution stories are those of recovery. They are dominated by the restoration of the self, as it was before the child's illness. They are culturally preferred and are supported and sustained by the medical model and health care institutions. Frank (1995) stated that they are the most common type of narrative and that "restitution stories attempt to outdistance mortality by rendering illness transitory" (p. 115).

All parents' experiences were well represented by narratives in which the restitution plot was dominant, and occurred typically during times in which parents suspected that something was wrong with their child (pre-diagnosis), and when they were beginning to accept the diagnosis of, and treatment for their child's cancer. For example, each parent's narrative began with the explanation of the troubling interruption in their lives of suspicious signs and symptoms of what often seemed to be a non-descript illness. The symptoms were insidious, and necessitated going back and forth to various doctors as symptoms prevailed, worsened, and became more difficult to explain. During this time, parental instincts were heightened, but all parents used restitution narratives to hope for 'the best outcome'. For example, the parent of a

child diagnosed ALL said, “my first thought was that I’m hoping that I’m being a crazy paranoid mom, to oh crap, it could be leukemia, to, I hope it is the good kind, I hope it is something we can overcome.” Another parent described her pre-diagnosis experience as follows:

I hoped it wasn’t going to be serious, you know. That the doctors were going to find that, oh, it was just an infection and you know we’re going to give him different medication and he’s going to be ok. Yeah, yeah. But honestly it, you know, it just went downhill very quickly and I kept thinking he’s going to be ok but then in the back of my mind I kept thinking this is serious. I think in the beginning we just hoped that he’s going to survive.

One parent’s restitution narrative projected a future in which she felt that life would no longer be disrupted by her child’s illness when she stated, “I just want to be positive and hopeful that this is just a bump in the road”.

Once their child was diagnosed and parents began to accept the diagnosis and the associated lengthy treatment phase, most of them consciously chose to live in ‘the moment’. Thus, many of the restitution narratives were prospective, providing hope for a better future, whether or not that future meant a return to health, or some aspect of peace for their child, even in death. This is contrary to Frank’s (1995) belief that restitution narratives do not work for chronic illness, or in death and dying because when such narratives don’t “work any longer, there is no other story to fall back on” (Frank, 1995p. 94). Perhaps the conflict with Frank’s proposition and parents’ use of restitution narratives is due to the idea that parents were contemplating death, and not experiencing the death of their child, or, that hope provided the courage to bear witness to such an unimaginable prospect. The following narrative illustrates elements of restitution when one parent described her ability to live life, albeit a painful one, in the event of her child’s death:

We can be hopeful no matter what the situation is. Even in a bad situation, your hope is still there, like my worst, my worst case scenario would be if he were to pass, but at the same time I would just be hopeful that I would have the support and the friends and the people around me that I would need just to get through that. So I think no matter what the

situation is, you can still be hopeful, and you can be hopeful that that pain that you're feeling, that pain would probably never go away but you could live with it.

Only three parents seemed to feel close enough to what they believed to be a future beyond their child's cancer in which survival was safe to contemplate. Their narratives are reminiscent of Frank's (1995) description of restitution narratives that depict a return to a normal life as it was just before the beginning of the impact felt by illness, and in which a future is no longer disrupted by childhood cancer. For all three parents, it was often a restitution narrative filled with trepidation. A single mother of a pre-adolescent boy who was diagnosed four and a half months before her first interview described her anticipation and excitement about being able to move beyond her son's illness stating:

There's excitement that it will be over. Like that he will be cured and he'll be able to go back to a normal life and normal kid life and do the things he wants to do. Like he's ecstatic right now because he's getting far enough in his treatment that he'll now be on the badminton team and be able to go to regular practices and have something normal for his grade 8 year so he's really excited about that which that makes me happy so. So yeah like just the whole excitement of it being done and being able to breathe normally again and that final sigh of 'uh, ok, it's finished'.

Similarly, a father whose son was nearing the end of his proposed treatment described getting back to a life like they had prior to childhood cancer through a restitution narrative in the following way:

He can play outside and not have to worry about coming back here every week for tests and chemo and stuff, just kind of get back to the normal where he's outside playing like a kid should be playing and not sitting in a hospital hooked up to machines. I, I guess just not having to worry about, you know, going for treatment. Like making any kind of plans, you could kind of just do whatever you wanted just like we did before. You know. Just make the plans and go here, go there, not worry about without taking him into big crowds or like he might get sick or catch something and, and always wondering, you know, when's the next test going to be or just kind of back to the way he was before the diagnosis. Kind of get up in the morning and do your thing and just get on with it.

Lastly, a mother of a toddler-aged daughter simply wrote in her journal, "today was a very unproductive, yet back to normal day at home. It was very nice to have a simple day of chores.

Life is feeling kind of normal and it is easy”. She succinctly stated that life was returning to an easy normal for her. Similarly, a mother of a young boy just diagnosed with ALL stated, “It feels like it’s normal, you know that we’ve adapted to a new normal. Just different vocabulary, new vocabulary, new people, that’s all.”

Restitution narratives were common for parents who were caring for their children in treatment for cancer. They occurred at various points in the parents’ experiences including pre-diagnosis, with the acceptance of their child’s cancer diagnosis, and when they were comfortable with contemplating the end of their child’s cancer treatment and a ‘normal life’ again. While restitution narratives were common among parents, and supported them in hoping for the best outcome, and in seeking a normal life again, so too, were chaos narratives.

5.5.2.2 Chaos narratives. Frank (1995) described chaos stories as those that are chaotic in the absence of narrative order. The chaos story teller is not heard to be telling the story of a “‘proper’ life, since life as in a story, one event is expected to lead to another” (p. 97). Frank (1995) contended that these stories can only be told in retrospect because those who experience such a dominant life plot, cannot at the time, achieve a reflective grasp of their experience. It may be difficult to listen to these stories because the teller reveals vulnerability, pain, and futility, and often the stories are told without a beginning, middle, or end (Frank, 1995).

Each parent told stories of chaos that interrupted restitution narratives intermittently throughout the treatment phase for childhood cancer. Most often, chaos narratives were revealed during diagnosis of the child’s cancer, and then intermittently in response to their child’s emotional and physical reaction to treatment, perceived lapses in parents’ own strength and courage, and during changes in phases of treatment in which parents felt that the familiarity of the current treatment phase would be replaced by the ‘unknown’ of the new treatment regime.

For example, at the time of hearing the diagnosis of her child's cancer, one parent's chaos narrative was highlighted by what Frank (1995) called "a staccato pacing of words" (p. 99):

It's like your, just like your whole world has stopped, and you don't know where to go from there, and you don't know what's going to happen, and you don't know whether people are going to be okay, or not, or how to fix it, or what to do about it.

The chaotic syntactic structure of this narrative was mirrored by another parent's comment when he recalled the time in which his son was diagnosed with cancer. He exclaimed, "I didn't know really what was going on, or what was going to happen, or how it would all end out, and I really don't remember a lot, the first few days. I was just in so much shock".

Although parents revealed chaos narratives in retrospect, their uncertainty and doubt were very clearly expressed and were still painfully close. In the following chaos narrative, a mother recalled her experience when her son was diagnosed with cancer, which as Frank (1995) claimed, had an incessant present. There was no discernible past, and the mother seemed incapable of anticipating a future. She said:

I, well, I was, I was expecting him to be, I guess, really sick for months and months, and to be, I guess going through hell, like we would see him just be so sick and, and at that time I, we didn't really, I guess, know or understand the, the success rate that they had with children's cancer. I didn't and I, I guess you know, I was thinking that we were going to lose him. So, and yeah, I just I just I guess I thought he was, it was going to be a really, really hard long battle for him and that he was going to be having to, I guess, be really sick. I think, like you know, we still had hope, and, and I think my, I was maybe at that time, it was everything was just getting in, so I don't know exactly what the, I don't even know. Sorry.

In this narrative, the mother's account is anxiety provoking for her and for those who hear it. Realizing that her words were broken, in fact, her heart was broken, she crumbled during the telling of this story, and she ultimately stopped, apologizing for her inability to express herself. This illustrates Frank's (1995) contention that chaos narratives are beyond speech, therefore,

lacking speech. He claimed, “words suggest its rawness, but that wound is so much of the body, its insults, agonies, and losses, that words necessarily fail it” (Frank, 1995, p. 98).

Chaos narrative types were also present throughout the treatment trajectory during transition from one phase of treatment to another in relation to their child’s health, and their own sense of strength and emotional health. This is exemplified in the following narrative in which a mother contemplated the upcoming change in a phase of treatment for her daughter who was diagnosed with cancer just two and a half months before:

She’s got a lot of new drugs that could potentially make her quite sick, and it’s scary, so I mean we kind of just have to hope that she does well for it, or through it, but uh we won’t know until that starts, and how she how she does. So, you know, we just got to hope and, and that ‘cause we’re worried and scared, ‘cause we don’t know how it’s going to go, because it’s a new phase for her, new drugs. So, so yeah we’re stressed out about that so I think that’s, yeah, kind of the same the fear, the stress of just the unknown. Fear of unknown, of unanswered questions.

This participant’s feelings of lack of control, fear, and uncertainty are reflected in another parent’s narrative in which she speaks of the reality of cancer and her desire to be strong and brave. She felt as though her parental control had been taken from her. Her speech is repetitious and fragmented, yet deliberate:

Yeah, it was kind of like, ‘oh here’s another’, when he like when his hair started falling out, it was like, it’s like another blow, I guess, it’s like, ok, this is real and this is happening and, and he loves his hair, like we couldn’t get him to get his hair cut, and so it was like never wanted this for him, you know, it you, you, but yeah. You want to put on a strong front so that he feels ok with the fact that we’ve got to shave his head. All I wanted to do was be strong enough for him so he wasn’t scared.

The experience of loss of control is indicative of chaos narrative types, and as Frank (1995) explains, “the chaos story presupposes *lack* of control ... Chaos feeds on the sense that no one is in control” (p. 100).

When attempting to contemplate life beyond cancer, one parent appeared to be caught up in a chaos narrative. She described her thoughts as follows:

Trying to get back to normal, I guess, is one of the big steps. I don't know. I don't feel like there's ever a normal any more. Not having to worry but feel normal. I think that's the big thing. Not always feeling like, to go back to not having to worry every day about this. I really don't know what normal is anymore it's been about a year, I know many people, I don't know I've been, I don't know how to find a normal or what that is. I just know that to get rid of that constant worry. That would be wonderful.

Not knowing what 'normal' was created a great deal of worry and discomfort for this parent.

Perhaps she required time and space to reflect upon the very life changing event that she had encountered with the diagnosis of her son's cancer, rendering a restitution or quest narrative impossible at that time. Frank (1995) contended that chaos "is never transcended but must be accepted before new lives can be built and new stories told" (p. 110).

Chaos narratives were present for all parents when control and familiarity were replaced with fear, and uncertainty of the unknown – when they experienced a loss of control. During the treatment phase of childhood cancer, parents described their experience as a 'roller coaster ride' with many ups and downs. Chaos narratives help parents share their turbulent experiences with others, and retrospectively reflect on an experience that at the time had no heads or tails. Chaotic stories seem to have a diabolical nature, both distressing and healing for the parents in this study. Conversely, the third narrative type, the quest narrative revealed how some parents were able to meet their challenging life circumstances head on.

5.5.2.3 Quest narratives. Frank (1995) defined quest narratives as those that are told in such a way that there is something that has been, or will be gained through the illness experience. Individuals see themselves in a future in which they recover health and wellness. Quest narratives convey a journey in which there is a beginning, replete with trials and tribulations. They continue to the point in which the tellers have reaped some benefit because of their experiences that they believe may be helpful to others. According to Frank (1995), quest stories "meet suffering head on; they accept illness and seek to *use* it" (p. 115).

In this sample, the dominance of the quest narrative was prominent in the accounts of some parents. For these parents, this narrative type was deeply entrenched within their parental care giving experiences, and they described newly gained strengths in parenting and a new appreciation for their child and family. For example, a father of two who worked outside the home, commented on his new appreciation for his relationship with his wife and with his children in the following account:

I've changed, uh maybe took a lot of things for granted before, whether it's work, or sports, and you know realizing now that he is, you know sick, you kind of take more time to spend with him and, and just listen to him a little bit more. I think it also goes back to like the people around me too, you just don't realize how short life really could be, and you, you kind of pay attention to the more final finer details of life. I guess you don't just fly through it, you just take your time and you appreciate more of the time that you spend with people or, or appreciate more of the things that you do. You don't just take it for granted because it's, you know, life can change pretty quick.

This description follows what Frank (1995) termed an automythology, one of three facets of the quest narrative type in which change at a personal level is highlighted. The same father also framed his change in a manifesto style of quest story that Frank (1995) stated was a prophetic truth that has been learned at a social, not just a personal level. The father described his experience as follows:

I mean my attitude toward maybe even other like charities and other sick kids it it kind of maybe hits me a little bit harder now that I realize you know I'm dealing with the same thing or a similar thing and I kind of feel for what everybody else is feeling.

Another father of a young son shared a very similar automythology style of quest narrative when he said:

This has taught me, and what (my son) has taught me, is I've learned to appreciate every second is a gift with him right now. It's like, 'dad want to color'? Absolutely. 'Dad want to play blocks with me?' Awesome. Sat on the floor and played blocks with him. I'll just hang with you and watch you. Living in the now. That's what I am doing now. I accept everything. I don't know where it's going to go, what kind of moment it's going to be, but if I accept it and offer back, that is living in the moment.

One mother's quest narrative described her life with a husband who worked outside the home, and the time and care she provided for her two children. She presented a memoir style of a quest story by including a description of her new way of analyzing and dealing with the activities of daily living:

I have so many girlfriends that stress about their days all day long about whether the beds are made and whether their laundry is done and the dishes, and I do have days that I feel that way, but a lot of the times I stop myself in my tracks and I think, you know what? This laundry and these dishes, they'll always be here. My kids won't be here. What's more important here, in this moment that you're in right now, what's more important? Yelling at your kids because they took all the Barbie's out of the box and left them on the floor, or get down and play with them and enjoy because one day those Barbie's aren't going to be there and you are going to wish that they were laying there. The simple things in life, like, I don't know, I think of all the things that are more important at that moment.

Another mother of two children began her memoir with the description of change that she had deliberately sought after experiencing the impact of illness. She explained how she and her children celebrated the small things, and clearly described how her focus in life had changed:

Some little things don't matter anymore, like a clean house, perfect yard, laundry. Other things, like getting to a Halloween party back home, take top priority. Yeah and I mean all in the way there's little tiny steps of that other people just really don't care, they take, you know, for granted right. 'Oh well he got up today, he ate 3 meals and he had a friend over'. Woo hoo 'cause he hasn't done that in 6 months, so anybody else who came home from school that day and you know had their 3 meals and brought a friend home the parents might say 'no no, we're busy tonight' and send them away, and I'm going, 'yeah yeah yeah come on come', so for him that's an improvement, like, so for me that's good let's have a cake and streamers and balloons so I mean we've celebrated ridiculous things in my family as far as you know the little things that everybody else would be 'yeah whatever she's 20 pounds', 'oh whatever, he had a friend over'.

A father shared a much more subtle quest narrative that also depicted the realization of a sense of purpose and Frank's (1995) sentiment that illness is seen as a journey. The father described his relationship with his daughter and his ongoing support for her through her illness journey. In this instance, he said:

You know if I can give her any sense of hope, it's that this is not a debilitating thing in your life, this is an awful experience that will be used to birth something far, far better. Far,

far more meaningful than probably we would have had without it. You know? This is all, all a building block for something else. Um, in many ways it's an awful experience that you've been entrusted with for whatever you're going to have, or be later.

Quest narratives were not as common as either the restitution, or chaos narrative types, and only some of the parents shared narratives in which quest stories were dominant. This may be because the parents' narratives were often disrupted by both restitution and chaos stories as they experienced the ups and downs of the roller coaster that they associated with treatment for childhood cancer. Their feelings of loss of control, fear, anxiety, and uncertainty dominated their lives to the extent that those parents had yet to construct a quest narrative. It is important to note that except for quest narrative types, all parents expressed their stories with a variation in dominance of narrative types. Frank (1995) contended, "no actual telling conforms exclusively to any of the three narratives" (p. 76).

5.6 Discussion

The insights gained from this analysis contribute to the existing literature related to parents who care for their children in treatment for cancer by illustrating how parents narrate their experiences. By drawing on Frank's (1995, 2010, 2012) narrative typology of illness, we discovered that there are unique ways in which parents journey through the different phases of their child's cancer treatment with their child and family. All parents recalled and expressed their experiences in a temporal fashion, but these experiences were turbulent, and cyclical. Their stories of restitution, chaos, and quest dominated their care giving experiences in relation to the different treatment stages, their child's physical and emotional reaction to those stages, and perceptions of social support and their own fortitude. This is the hallmark and the usefulness of narrative analysis guided by Frank's (1995) narrative types. As he stated so eloquently, "the three narratives are like patterns in a kaleidoscope: for a moment the different colors are given

one specific form, then the tube shifts and another form emerges” (p. 78). This unique perspective highlights the importance and value of the findings of this study.

Findings from other studies support the current study findings. In this study, restitution narratives were commonly used by all parents, and were most often heard during the time before diagnosis of the child’s cancer when the diagnosis was accepted, and for some parents, during the later stages of treatment. These narratives reflected parents’ excitement about life returning to a normal state, a life that would be uninterrupted by childhood cancer. Restitution narratives also supported parents in hoping for the best outcome, even when parents contemplated the worst-case scenario, the death of their child. Similarly, the families in Wong and Chan’s (2006) phenomenological study of families who had children in treatment for cancer were reportedly looking forward to a normal life. Other studies found that parents sought to establish a sense of a normal life in which elements of their child’s illness did not interrupt the normal activities of daily living (Angstrom-Brannstrom, Norberg, Strandberg, Soderberg, & Dahlqvist, 2010; Huang, Mu, & Chiou, 2008). Miedema, Hamilton, Fortin, Easley, and Matthews (2010) found that parents of children diagnosed with cancer (5 were still in active treatment) tried to maintain a level of normalcy in which life carried on as though their child was not sick. Thus, although the existing literature provided evidence that establishing a normal routine is important to parents, there is little information supporting the notion that parents seek a future in which a normal state of health is discovered. Although restitution narratives were relevant and helpful to the parents in this study because they may have supported them in developing the hope and courage required to face the long journey associated with treatment of their child’s cancer, and in hoping for a better future, additional research is required to examine these narratives to determine how best they can serve parents.

Chaos narratives demonstrated that parents experienced periods of fear, anxiety, uncertainty and a loss of control. These experiences occurred at the time of diagnosis of their child's cancer when treatment phases ended and new ones were implemented, and when parents evaluated their own and their child's emotional and physical health negatively. Consistent with the findings of this study, McGrath (2002) and Woodgate and Degner (2002) revealed that families of children with a variety of childhood cancers, experienced a roller-coaster ride with many ups and downs during which time they experienced a wide range of feelings and emotional pain. In their study, Woodgate and Degner (2002) provided a narrative clip that captured the essence of a chaos narrative from a mother describing her inability to make sense of the future given the many unknowns associated with childhood cancer. While a number of other authors did not focus specifically on narratives, they reported stressful, anxiety provoking parental reactions that resulted in difficulty getting through the day and self-care (Fletcher, Schneider, & Harry, 2010; James et al., 2002), a disruption in daily routines and activities (Hildenbrand, Clawson, Alderfer, & Marsac, 2011; Patistea, Makrodimitri & Panteli, 2000), and in ineffective coping behaviors such as substance abuse (Miedema, Hamilton, Fortin, Easley, & Matthews, 2010), all of which may have created chaos in the parent's lives.

The current study provides unique contributions to the understanding of parental experiences with respect to the chaos that is experienced not only at diagnosis, but throughout their child's treatment. It is critical to consider that, perhaps, parents may be unable to understand themselves, or relate to others their current chaotic experiences. Such narratives may become invisible (Frank, 1995), but they are experienced nevertheless. Future research that focuses on this particular experience will enhance our understanding of parental reactions, and

will help practitioners become attuned to this potentially silent experience, and thus, be better able to support and guide parents through this most challenging time.

Quest narrative types were not as common as the restitution and chaos narratives. Quest narratives were descriptions of parents' journeys through their child's treatment for cancer phases, and typically involved a description of their choice to make positive changes in relation to their parenting and outlook on family life. These parents told of living in the moment and gaining a new appreciation for life, their family, and children. Similarly, Clarke-Steffan (1997) found that families whose child was diagnosed with cancer constructed a 'new normal' that involved a number of different strategies including evaluating priorities. These parents described finding a new appreciation for life, family and time together, and no longer took things for granted. Other studies found that parents who have children in treatment for cancer found positive gains from their experience (Fletcher, Schneider, & Harry, 2010; Wong & Chan, 2006), including strengthened relationships among family members (Brody & Simmons, 2007; James, et al., 2002; Patistea, 2005; Sloper, 1996), and on reprioritizing time spent with their child (Brody & Simmons, 2007). Quest narratives are an important aspect of the parental experience, but few parents engaged in this narrative type. Additional research can assist in developing knowledge regarding the internal and external factors that support the quest narrative type because it is an important aspect of parental well-being. Further examination of the ways in which parents develop meaning and purpose from their child's illness experience, and how this contributes to parental well-being and care giving during their child's treatment is essential.

The literature related to parents of children with cancer has established support for each of Frank's (1995, 2010, 2012) narrative types. What is unique about the findings of this study, however, is that each narrative type is presented as only one instance of a very complex and

changing parental experience, each of which cannot be understood in isolation from the others. The holistic understanding that is provided contributes to a comprehensive understanding of parental experiences, and highlights the need to attend to the specific narrative type parents are presenting in order to support them adequately.

5.7 Factors Influencing the Study

As with all qualitative research, the dialogical and interpretive nature of Frank's analysis in this study may not be generalized to other populations. Because the sampling strategy is purposive, there was some homogeneity found in the sample such as those who were Caucasian, female, and Christian. In addition, Frank's analysis leads to narratives that are co-constructed between the researcher and the participant, and are considered to be ever evolving with no distinct ending. The use of only three narrative types suggests the need for more diverse analyses using different forms of narrative analysis. This would enhance our understanding of the complexities of parents' experiences. Future research using a variety of clinical populations in pediatrics, longitudinal studies, or studies that uncover processes over time with a more heterogeneous sample are required. For example, such studies may include those of other ethnicities and cultures, as well as studies in which fathers are well represented. However, the findings likely have theoretical transferability, and may well represent situations that are recognizable in other contexts, and therefore, may be useful to a variety of researchers and clinical practitioners in other settings.

5.8 Implications for Practice

The findings from this study reveal that restitution, chaos, and quest narrative types are all present in parental experiences gained from caring for their child who is in active treatment for cancer, and that their experiences are individualized, unique, and contextualized. Attending to

parents' communication in an open and focused manner can help clinicians to honor and validate their stories, and thus, their experiences. Frank (1995) contended that illness disrupts the lives of those who are ill and who are impacted by illness, and it is through telling one's story that some semblance of coherence can be found, and this facilitates the putting back together of the self. This understanding can improve holistic and comprehensive assessments, and thus, interventions can be adequately guided and focused. A parent whose current experience is being told through a restitution narrative needs to be supported in living through their child's illness and in preparing for the future. Helping parents to get through the trials and tribulations of the various treatment phases may include supporting their faith in the treatment they are receiving, and in envisioning a realistic future. Those parents whose narratives are chaotic need to be assisted in their experience and not rushed into another narrative type. They need to be supported in developing tolerance for, and space to experience and then to reflect on the chaos in their lives, and to acknowledge that in time, the chaos does retreat. In addition, careful, ongoing assessment is required to monitor those parents who may be at risk for giving up, for losing hope, and who may be exhausted, depressed, or anxious. Lastly, those parents whose experiences are expressed through a quest narrative type can be supported in their pursuit of making meaning out of, and in finding purpose in their current situation.

5.9 Conclusion

Polkinghorne (1988) stated that narratives are "the primary form by which human experience is made meaningful" (p. 1). Thus, a critical understanding of findings from analyses that incorporate illness narratives can aid researchers and practitioners in understanding unique parental perspectives. This understanding can provide the means for helping parents understand

their experience more clearly, as well as the necessary individualized support and guidance they need through the various stages of their child's cancer treatment.

SECTION 6

IMPLICATIONS OF THE FINDINGS AND CONCLUSIONS

6.0 Implications of the Findings

The developing constructivist grounded theory of keeping hope possible, and the narrative analysis findings represent data from 16 parents who had children in treatment for cancer. The emerging theory adds unique insight into the hope experiences of parents whose children are undergoing treatment for cancer. By having access to a clearly defined concept of parental hope, health care providers may be better able to understand and assess these parents in order to support their hope, and to determine when they are finding it harder to hope. Because hope is essential, dynamic, and acts as a guide through the tremendously challenging oscillation between preparing for the worst and hoping for the best, supportive needs and interventions will vary depending on where parents are on that continuum. Informed, open discussion, and a holistic assessment that considers parental hope are necessary.

6.0.1 Implications for Nursing Practice

Parents' desire to keep hope possible is a major and unique finding in this study. There are four distinct, but interrelated subprocesses of keeping hope possible, each of which may support comprehensive and holistic nursing care for parents who have children in treatment for cancer. The first subprocess, '*accepting reality*' is one in which parents go through an intense period of shock, questioning, and reasoning. It would seem that at this stage, parents need to tell, retell, and tell again their experiences in order to make sense of their own story, and to come to an understanding that will allow them to accept their unique and individual past, present, and future so that they can begin to focus their hope and move forward for themselves, their child, and their family. Frank (1995) firmly believed that serious illness is like a wreckage, disrupting life's map and destination. This is certainly mirrored in parents' descriptions of their experiences with childhood cancer as both 'life changing', and 'traumatic'. Frank (1995) contended that stories were a means to redrawing those maps and to finding new destinations. Stories are like repair

work. Most importantly, Frank stated that “the act of telling is a dual reaffirmation. Relationships with others are reaffirmed, and the self is reaffirmed” (p. 56). Health care providers can be the expert, active, and attentive listeners who are needed to help provide parents with guidance through this difficult and seemingly impossible phase of keeping hope possible. Listening to parents and encouraging them to narrate their experiences when they are ready and able, may support them in the necessary repair work “by taking stock of what survives the storm” (Frank, 1995, p. 54). Without this challenging work, parents may be unable to move forward to find their hope, an essential component of their daily lives, well-being, and caregiving.

Next, ‘*establishing control*’ follows as another essential related process through which parents journey in keeping hope possible. Understanding this subprocess is essential for health care providers because it underlines the need to allow, and to support parents as they cognitively journey through the depths of darkness in the worst-case scenario. Each parent discussed the negatives, the what ifs, and the worst case scenario, vividly recalling such activities as planning the eulogy for their child’s funeral, whether, or not, the child’s room would be emptied, and visualizing themselves at the funeral. Thus, whether voluntarily, or involuntarily, parents had to prepare themselves for the possibility of their child’s death, and more importantly to be able to face personally what seemed like the unimaginable. Parents did not want to be blindsided or ‘taken for a fool’, but also felt guilty for allowing their thoughts to go to such extremes. Knowledge of these complex experiences and the important role that hope plays, can help both parents and health care providers to develop the insight needed to prepare for the oscillation between preparing for the worst, and hoping for the best. Knowing what to expect may assist parents in moving through this subprocess more effectively, and knowing that it is an expected

and common part of hope, may provide them with a heightened sense of control and some direction in what would otherwise be a chaotic and uncontrolled experience.

'Restructuring hope' was another important subprocess in parents' hope experience and this allowed them to find their hope again. Supporting parents in recognizing their hope and in their need to be hopeful can help them to navigate through this subprocess successfully. In addition, understanding the ability of parents to restructure their hope may provide insight into how parents cope with their child's cancer experience such as their need for honest, timely information. Parents said that they wanted to be kept in the loop "no matter what – the good, or bad, or otherwise", and that information and knowledge supported their hope. Thus, if communicated in a timely, open, and honest manner, poor test results, prognoses, and plans can indeed be accepted by parents because they can restructure their hope so as to keep it possible, and it can then be used to cope with the related ups and downs of such news.

Lastly, *'purposive positive thinking'* was the final subprocess of keeping hope possible. Understanding the incredible strength of the human mind and spirit is essential for both parents and health care providers. This essential subprocess of parental hope can be supported by assisting parents in choosing to think positively when they are ready, and by helping them to find and use cognitive strategies that will suit their needs and abilities in order to begin the training process. Some parents in this study found visualization and imagination of potential positive outcomes, practicing their own unique hopefulness, deep breathing and focusing repeatedly on happy thoughts, to be helpful in training themselves to think positively and to eradicate negative thoughts. In addition, parents suggested that a positive and hopeful support system is necessary to support their hope and positive thinking. Helping parents find their support structure may assist them in thinking positively, and in keeping their hope possible. Lastly, acknowledgement

that there is a positive reported by parents in this traumatic and challenging experience may help them to find focus for their hope, and to identify those areas in which they may experience personal, parenting, spiritual growth, as well as growth in their social relationships.

6.0.2 Implications for Nursing Research

Based on the findings in this research study, additional research is required to compare and contrast, and therefore, to develop further, the definition of hope and the developing grounded theory for parent groups such as this one. Future research is also needed to investigate the impact that childhood cancer may have on, and how hope is experienced by the whole family unit, including siblings, parents' work life, those of other cultures, and parents with a variety of religious preferences. Such research, using samples of families of children with a variety of life threatening and life limiting illnesses, and those who have children in different stages of cancer can add invaluable information to this area of study. Additional research can support the development of the key concepts that appear to be related to hope including, anxiety, fear, and uncertainty which will help to guide nursing care more effectively. Particular attention to the transitions that parents must go through as their child is treated for cancer is warranted. A greater understanding of these experiences may assist health care providers to reduce the impact that these experiences have on parents, and therefore, support them in keeping their hope possible. Using different methodologies to explore and examine parental hope will add to the emerging theory presented in this study. Such studies will support the development of appropriate methods of assessment of parental hope, as well as interventions to support parents adequately as they provide care for their child who is in treatment for childhood cancer.

6.1 Overall Conclusions

Through the development of three separate manuscripts including a literature review and analysis, a constructivist grounded theory study, and a narrative analysis, this research broadly sought to explore parents' hope experiences. A constructivist grounded theory was used to conduct the study of parental hope experiences. This grounded theory approach is supported by symbolic interactionism, a theoretical position that suggested human beings adapt and change their understandings and behaviour largely dependent on the three core principles of meaning, language, and thought. The reality of the parents in this study was one of change, depending on the transitions related to treatment for childhood cancer. As a result, parents moved from the shock of the diagnosis of childhood cancer, through to various transitions depicted in the road map with which they were provided, and which mapped out the phases of treatment for their child. In addition, this study revealed that the very nature of parental hope is dynamic. The parents' main concern was 'fearing the loss of hope'. This occurred when they were presented with the uncertainty associated with the transitions that were inherent in the treatment for their child's cancer. However, the basic social process of 'keeping hope possible' was supported by the subprocesses of accepting reality, establishing control, restructuring hope, and purposive positive thinking. These subprocesses were interrelated, but cyclical, fluid, and changing as parents journeyed through the treatment phases of childhood cancer. Together they supported parents in the very difficult movement between hoping for the best and preparing for the worst. The use of symbolic interactionism as a guide, helped to make sense of the parents' changing meanings, thoughts, and hope experiences throughout their journey.

The first specific objective of this study was to gain an interpretive understanding of the hope experience and processes of hope for parents who have children who were undergoing

treatment for childhood cancer. One of the hallmarks of Charmaz's (2006) constructivist grounded theory approach, and Frank's (1995) narrative analysis is the emphasis on the active interpretive role of the researcher, and the importance of reflexive research practice. During the 13 months of data collection and analysis, continuous reflexive practice contributed to an enhanced understanding of the interview process, data collection and data analysis, particularly with coding, the development of categories, and the need for theoretical saturation. Through reflexive research, my background as a registered nurse, a daughter, mother, and researcher were all examined, acknowledged, and this solidified my understanding of the data. For example, I believe the shared commonalities of being a parent, the experience and practice of being a registered nurse, and the knowledge of my role as an ethical researcher allowed me to connect with the parents in this study in a manner that was comfortable and trustworthy. After the first few interviews, I found that my connection with parents, as a mother, was emotionally difficult because it was, of course, difficult to see a parent experience the 'unthinkable', and their experiences 'hit home'. The parents' stories were real, true, and as Frank (1995) contended, they created in me a very real awareness that childhood cancer can occur in any one of our children and families. In the first few interviews, my empathy may have prevented me from asking 'the hard questions', but through reflexive practice, I remedied this by understanding and acknowledging my thoughts and feelings, and by specifically making the effort to go to those difficult places with parents. I soon learned that I was able to support and guide parents through these sometimes sad and challenging discussions, in part, because of my experience as a registered nurse. With adequate debriefing, following each interview, parents often found that it was helpful for them to think about, feel, and sometimes resolve certain experiences that were difficult. I believe that through my varied experiences and background, I was able to connect

effectively with the parents in this study. Each interview was at times difficult, but it was always a constructive sharing of discussion through which deep, rich data were collected, and which led to the development and saturation of the theoretical categories. My interpretation of the data was closely and continually reflected upon, shared frequently in a confidential, and collaborative research environment with my co-supervisors, and was grounded in the data that were supported by verbatim quotes from the participant interviews. Following Charmaz's (2006) evaluative criteria for grounded theory studies, these endeavours helped to achieve resonance and credibility for this study.

The second, specific objective of this study was to describe and define parental hope and significant related concepts for parental caregivers within their social context. Both Charmaz (2006), and Frank (1995, 2010, 2012) offer a flexible, non-prescriptive approach to the research process. For example, an open and flexible interview process allowed me to focus on participant responses and change the way I listened and responded to the participants' words. This led to rich and focused data collection, to the effective saturation of the categories, and to sampling parents theoretically to support this endeavour. As a result, a definition of the parents' hope was constructed from their description of their parental experiences and from their own words. This study revealed that parental hope is a powerful, deliberate, life sustaining, dynamic, cyclical process that is anchored in time, and is both calming and strengthening, and provides inner guidance through the challenging, but necessary experience of preparing for the worst and hoping for the best. This is one of the unique findings of this study, and it presents a definition that is not described in the existing literature. This conceptualization of parental hope is important because it can guide more informed nursing assessment and care, and can provide

direction for future research. Thus, this aspect of the research study meets Charmaz's (2006) criteria for originality and usefulness.

The third and final specific objective of this study was to construct a tentative substantive theory that was grounded in the experiences of parents who cared for their child who was in treatment for cancer. In comparison to the studies that were reviewed for this research, this study included a homogeneous sample in the sense that only parents who had children in active treatment for cancer were participants. This permitted a unique focus on the experiences of this population. In addition, diversity within this sample was obtained through purposive theoretical sampling, seeking participation from both mothers and fathers, including parents from rural and urban settings, those in married, single, and common-law relationships, parents with varied ethnic and spiritual backgrounds, different ages and genders of their children, varied lengths of time between diagnoses and the first interview, and from different childhood cancer diagnoses. In addition, the method of constant comparative analysis was used to support the development of a tentative theory that was well grounded in the experiences of a diverse and informed sample. Constant comparative analysis kept me grounded in the data, and supported the systematic comparison of each parent's hope experience, as well as the ongoing analysis of the related contextual influences. The constructivist approach of 'weaving in' the extant literature to the theoretical rendering of keeping hope possible both substantiated and added credibility to this study, and demonstrated the unique value of some of the findings. The resulting grounded theory, keeping hope possible, is the first emerging theory that describes the hope experience of parents who have children in treatment for cancer, and therefore, adds empirical support for the abstract and complex concept of parental hope. Additional research is needed to explore and confirm the meaning of parental hope, and to support the tentative theory of 'Keeping Hope

Possible'. However, the findings in this study present new empirical evidence that enhances our understanding about the meaning and processes of the hope experiences of parents who have children in active treatment for cancer, key elements in their own health and wellbeing.

REFERENCES

- Amendolia, B. (2010). Hope and parents of the critically ill newborn. *Advances in newborn care*, 10(3), 140-144.
- Angstrom-Brannstrom, C., Norberg, A., Strandberg, G., Soderberg, A., & Dalqvist, V. (2010). Parents' experiences of what comforts them when their child is suffering from cancer. *Journal of Pediatric Oncology Nursing*, 27(5), 266-275.
- The Association for Children's Palliative Care. (2009). *ACT's charter for children and families*. Retrieved from <http://www.act.org.uk/page.asp?section=56§ionTitle=ACT%27s+charters+for+children+and+families>
- Bally, J. M. (2012). A Grounded Theory Study of the Hope Experience of Parental Caregivers Who Have Children in Treatment for Childhood Cancer: Keeping Hope Possible. Manuscript in preparation.
- Barerera, M., D'Agostino, N. M., Gibson, J., Gilbert, T., Weksberg, R., & Malkin, D. (2004). Predictors and mediators of psychological adjustment in mothers of children newly diagnosed with cancer. *Psychooncology*, 13(9), 630-641.
- Barrett, E. A. M. (2002). What is nursing science? *Nursing Science Quarterly*, 15(1), 51-60. doi: 10.1177/089431840201500109
- Benzein, E. G., & Berg, A. C. (2005). The level of and relation between hope, hopelessness and fatigue in patients and families in palliative home care. *Palliative Medicine*, 19, 234-240.
- Benzein, E., & Savemen, B. I. (1998). One step towards the understanding of hope: A concept analysis. *International Journal of Nursing Studies*, 35(6), 322-329.

- Best, M., Streisand, R., Catania, L., & Kazak, A. E. (2001). Parental distress during pediatric leukemia and posttraumatic stress symptoms (PTSS) after treatment ends. *Journal of Pediatric Psychology, 25*(6), 299-307.
- Bjork, M., Wiebe, T., & Hallstrom, I. (2005). Striving to survive: Families' lived experiences when a child is diagnosed with cancer. *Journal of Pediatric Oncology Nursing, 22*(5), 265-275.
- Blumer, H. (1969). *Symbolic interactionism: Perspectives and method*. Englewood Cliffs, NJ: Prentice Hall.
- Borneman, T., Stahl, C., Ferrell, B. R., & Smith, D. (2002). The concept of hope in family caregivers of cancer patients at home. *Journal of Hospice and Palliative Nursing, 4*(1), 21-33.
- Brody, A. C., & Simmons, L. A. (2007). Family resiliency during childhood cancer: The father's perspective. *Journal of Pediatric Oncology Nursing 24*, 152-165.
- Brown, K. A., & Barbain, O. A. (1996). Gender differences in parenting a child with cancer. *Social Work in Health Care, 22*(4), 53-71.
- Brown, R. T., Madan-Swain, A., & Lambert, R. (2003). Posttraumatic stress symptoms in adolescent survivors of childhood cancer and their mothers. *Journal of Traumatic Stress, 16*, 309-318.
- Browne, A. J. (2000). The potential contributions of critical social theory to nursing science. *Canadian Journal of Nursing Research, 32*(2), 35-55.
- Canadian Cancer Society Steering Committee on Cancer Statistics, *Canadian Cancer Statistics 2011*, Toronto, ON: Canadian Cancer Society: 2011.

Canadian Childhood Cancer Surveillance and Control Program, Diagnosis and Initial Treatment and Cancer in Canadian Children 0-14 Years, 1995-2000, Ottawa, Canada, 2003.

Chao, C. C., Chen, S. H., Wang, C. Y., Wu, Y. C., & Yeh, C. H. (2003). Psychosocial adjustment among pediatric patients and their parents. *Psychiatry and Clinical Neurosciences*, *57*, 75-81.

Charmaz, K. (2000). Grounded theory. Objectivist and constructivist methods. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed.) (pp. 509-535). Thousand Oaks, CA: Sage.

Charmaz, K. (2005). Grounded theory in the 21st century: Applications for advancing social justice studies. In N.K. Denzin & Y.S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed.) (pp. 507-535). Thousand Oaks, CA: Sage.

Charmaz, K. (2006). *Constructing grounded theory. A Practical Guide Through Qualitative Analysis*. London: Sage Publications.

Charmaz, K. (2009). Shifting the grounds. Constructivist grounded theory methods. In Morse, Stern, Corbin, Bowers, Charmaz & Clarke (Eds) *Developing Grounded Theory. The Second Generation* (pp. 127-154). Walnut Creek, CA: Left Coast Press.

Clark, A. M. (1998). The qualitative-quantitative debate: Moving from positivism and confrontation to post-positivism and reconciliation. *Journal of Advanced Nursing*, *27*(6), 1242-1249. doi: 10.1046/j.1365-2648.1998.00651.x

Clarke, N. E., McCarthy, M. C., Downie, P., Ashley, D. M., & Anderson, V. A. (2009). Gender differences in the psychosocial experience of parents of children with cancer: A review of the literature. *Psycho-Oncology*, *18*(9), 907-915.

- Clarke-Steffen, L. (1997). Reconstructing reality: Family strategies for managing childhood cancer. *Journal of Pediatric Nursing*, 12(5), 278-287.
- Cody, W. K. (1995). About all those paradigms: Many in the universe, two in nursing. *Nursing Science Quarterly*, 8(4), 144-147. doi:10.1177/089431849500800402
- Cody, W. K., & Kenney, J. W. (2006). *Philosophical and theoretical perspectives for advanced nursing practice*. Sudbury, MA: Jones and Bartlett Publishers International.
- Connelly, T. W. (2005). Family functioning and hope in children with juvenile rheumatoid arthritis. *The American Journal of Maternal Child Nursing*, 30(4), 245-250.
- Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage.
- Cull-Wilby, B. L., & Pepin, J. I. (1987). Towards a coexistence of paradigms in nursing knowledge development. *Journal of Advanced Nursing*, 12(4), 515-521.
doi: 10.1111/j.1365-2648.1987.tb01361.x
- Cutcliffe, J. R. (1997). Towards a definition of hope. *The International Journal of Psychiatric Nursing*, 3(2), 319-332.
- Cutcliffe, J. R., & Herth, K. A. (2002). The concept of hope in nursing 1: Its origins, background and nature. *British Journal of Nursing*, 11(12), 832-840.
- Dagnone, T. (2009). For Patients' Sake. Patient First Review Commissioner's Report to the Saskatchewan Minister of Health. Accessed December 3, 2009, from www.health.gov.sk.ca/patient-first-review/

- Dahlquist, L. M., Czyewski, D. I., & Jones, C. L. (1996). Parents of children with cancer: A longitudinal study of emotional distress, coping style, and marital adjustment two and twenty months after diagnosis. *Journal of Pediatric Psychology, 21*, 541-554.
- De Graves, S. & Aranda, S. (2005). When a child cannot be cured-reflections of health professionals. *European Journal of Cancer Care, 14*(2), 132-140.
- Denzin, N.K., & Lincoln, Y.S. (2005). Introduction: The discipline and practice of qualitative research. In N.K. Denzin and Y.S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (3rd ed., pp. 1-32). Thousand Oaks, CA: SAGE.
- Denzin, N. K., & Lincoln, Y. S. (2011). Part II: Paradigms and Perspectives in Contention. In N. K. Denzin and Y. S. Lincoln (Eds), *The SAGE Handbook of qualitative research* (4th ed., pp. 91-227). Thousand oaks, CA: SAGE.
- Dockerty, J. D., Williams, S. M., McGee, R., & Skegg, D. C. G. (2000). Impact of childhood cancer on the mental health of parents. *Medical and Pediatric Oncology, 35*, 475–483.
- Duffault, K., & Martocchio, B. C. (1985). Hope: Its spheres and dimensions. *Nursing Clinics of North America, 20*(2), 379-391.
- Duggleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C., & Williams, A. (2010). Metasynthesis of the hope experience of family caregivers of persons with chronic illness. *Qualitative Health Research, 20*(2), 148-158.
- Eapen, V., Mabrouk, A., & Bin-Othman, S. (2008). Attitudes, perceptions, and family coping in pediatric cancer and childhood diabetes. *Annals of the New York Academy of Sciences, 1138*(1), 47-49.

- Eapen, V., & Revesz, T. (2003). Psychosocial correlates of paediatric cancer in the United Arab Emirates. *Support Care Cancer*, 11, 185-189.
- El-Gamal, E. & Long, T. (2010). Anticipatory grieving among parents living with a child with cancer. *Journal of Advanced Nursing*, 66(9), 1980-1990.
- Elliott, J. A. (2005). *Interdisciplinary Perspectives on Hope*. Hauppauge, New York: Nova Science Publishers.
- Farran, C., Herth, K., & Popovich, J. (1995). *Hope and hopelessness: Critical clinical constructs*. Thousand Oaks, CA: Sage.
- Fawcett, J., & Garity, J. (2009). *Evaluating research for evidence-based nursing practice*. Philadelphia, PA: Davis.
- Fletcher, P. C., Schneider, M. A., & Harry, R. J. (2010). How do I cope? Factors affecting mothers' abilities to cope with pediatric cancer. *Journal of Pediatric Oncology Nursing*, 27(5), 285-298.
- Forbes, D., King, K., Kusher, K., Letourneau, N., Myrick, A., & Profetto-McGrath, J. (1999). Warrantable evidence in nursing science. *Journal of Advanced Nursing*, 29 (2), 373-379. doi: 10.1046/j.1365-2648.1999.00898.x
- Forte, L. S. (1997). The meaning of hope to family caregivers of children with Sickle Cell Anemia. Unpublished master's thesis, University of Alabama, Birmingham, Alabama, USA.
- Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago, IL: University of Chicago Press.

- Frank, A. W. (2010). *Letting stories breathe. A socio-narratology*. Chicago, IL: University of Chicago Press.
- Frank, A. W. (2012). Practicing dialogical narrative analysis. In J. A. Holstein & J. F. Gubrium (Eds). *Varieties of narrative analysis* (pp.33-46). Thousand Oaks, CA: Sage.
- Friebert, S. (2009). *NHPCO facts and figures: Pediatric palliative and hospice care in America*. Alexandria, VA: National Hospice and Palliative Care Organization.
- Gerhardt, C. A., Gutzwiller, J., Huiet, K. A., Fischer, S. Noll, R. B., & Vannatta, K. (2007). Parental adjustment to childhood cancer: A replication study. *Families, Systems and Health*, 25, 263-275.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine.
- Gortner, S. R. (1993). Nursing's syntax revisited: A critique of philosophies said to influence nursing theories. *International Journal of Nursing Studies*, 30(6), 477-488.
doi:10.1016/0020-7489(93)90019-Q
- Grootenhuis, M. A., & Last, B. F. (1997). Adjustment and coping by parents of children with cancer. A review of the literature. *Support Care Cancer*, 5, 466-484.
- Guba, E. G. (1990). *The paradigm dialogue*. Newbury Park, CA: Sage Publications. Guba, E. G., & Lincoln, Y. S. (2005). Paradigmatic controversies, contradictions, and emerging confluences. In N.K. Denzin and Y.S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (3rd ed., pp. 191-216). Thousand Oaks, CA: Sage Publications.
- Han, H-R. (2003). Korean mother's psychosocial adjustment to their children's cancer. *Issues and Innovations in Nursing Practice*, 44(5), 499-506.

- Herth, K. A. (1993). Hope in family caregivers of terminally ill people. *Journal of Advanced Nursing*, 18(4), 538-548.
- Hildenbrand, A. K., Clawson, K. J., Alderfer, M. A., & Marsac, M. L. (2011) Coping with pediatric cancer: Strategies employed by children and their parents to manage cancer-related stressors during treatment. *Journal of Pediatric Oncology Nursing*, 28(6), 344-354.
- Hoekstra, J. E., Jaspers, J. P., Kamps, W. A., & Klip, E. C. (1998). Marital dissatisfaction, Psychological distress, and the coping of parents of pediatric cancer patients. *Journal of Marriage and the Family*, 60, 1012-1021.
- Hoekstra, J. E., Jaspers, J. P., Kamps, W. A., & Klip, E. C. (2001). Psychological adaptation and social support of parents of pediatric cancer patients: A prospective longitudinal study. *Journal of Pediatric Psychology*, 26(4), 225-235.
- Hoekstra-Weebers, J. E., Jaspers, J. P., Kamps, W. A., & Klip, E. C. (2001). Psychological adaptation and social support of parents of pediatric cancer patients: a prospective longitudinal study. *Journal of Pediatric Psychology*,
- Holtslander, L. F., & Duggleby, W. (2009). The hope experience of older bereaved women who cared for a spouse with cancer. *Qualitative Health Research*, 19(3), 388-400.
- Horton, T. V. & Wallander, J. L. (2001). Hope and social support as resilience factors against psychological distress of mothers who care for children with chronic physical conditions. *Rehabilitation Psychology*, 46(4), 382-399.
- Huang, I. C., Mu, P-F., & Chiou, T-J. (2008). Parental experience of family resources in single-parent families having a child with cancer. *Journal of Clinical Nursing*, 17, 2741-2749.

- Hutchinson, S. A., Wilson, M. E., & Wilson, H. S. (1994). Benefits of participating in research interviews. *Image: Journal of Nursing Scholarship*, 26, 161-164.
- International Children's Palliative Care Network. (2008). Retrieved from <http://www.icpcn.org.uk/page.asp?section=000100010035§ionTitle=Definitions>
- James, K., Keegan-Wells, D., Hinds, P. S., Kelly, K. P., Bond, D., Hall, B., et al. (2002). Perceptions of caregiving demands. *Journal of Pediatric Oncology Nursing*, 19(6), 218-228.
- Jevne, R. (1991). *It all begins with hope*. San Diego, CA: Lura Media.
- Jevne, R. (2005). Hope: The simplicity and complexity. In J. Eliot (Ed.), *Interdisciplinary perspectives on hope* ((259-291). New York: Nova Science.
- Johnson, J.L. (1991). Nursing Science: Basic, applied, or practical? Implications for the art of nursing. *Advances in Nursing Science*, 14(1), 7-16.
- Kars, M.C., Duijnste, M. S., Pool, A., van Delden, J. J., & Grypdonck, M.H. (2008). Being there: parenting the child with acute lymphoblastic leukemia. *Journal of Clinical Nursing*, 17, 1553-1562.
- Kars, M. C., Grypdonck, M. H., Beishuizen, A., Meijer-van den Bergh, E. M., & van Delden, J. J. (2010). Factors influencing parental readiness to let their child with cancer die. *Pediatric Blood Cancer*, 54, 1000-1008.
- Kashdan, T. B., Pelham, W. E., Land, A. R., Hoza, B., Jacob, R. G., Jennings, J. R., ... Gnagy, E. M. (2002). Hope and optimism as human strengths in parents of children with externalizing disorders: Stress is in the eye of the beholder. *Journal of Social and Clinical Psychology*, 21(4), 441-468.

- Kauser, S., Jevne, R. F., & Sobsey, D. (2003). Hope in families of children with developmental disabilities. *Journal on Developmental Disabilities*, 10(1), 35-46.
- Kazak, A. E., Prusak, A., McSherry, M., Simms, S., Beele, D., Rourke, M. T., et al. (2001). The psychosocial assessment tool (PAT): Pilot data on a brief screening instrument for identifying high risk families in pediatric oncology. *Families, Systems and Health*, 19, 303-317.
- Kim, H. S. (1999). Critical reflective inquiry for knowledge development in nursing practice. *Journal of Advanced Nursing*, 29(5), 1205-1212. doi: 10.1046/j.1365-2648.1999.01005.x
- Kincheloe, J. L., & McLaren, P. (2005). Rethinking critical theory and qualitative research. In N. K. Denzin and Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (3rd ed., pp. 303-342). Thousand Oaks, CA: Sage Publications.
- Kirpalani, P., Parkin, A.R., Willan, D.L., Fehlings, P.L., Rosenbaum, D., King, & Van Nie, A.J. (2000). Quality of life in Spina Bifida: importance of parental hope. *Archives of Disease in Childhood*, 83(4), 293-297.
- Klassen, A., Raina, P., Reineking, S., Dix, D., Pritchard, S., & O'Donnell, M. (2007). Developing a literature base to understand the caregiving experience of parents of children with cancer: a systematic review of factors related to parental health and well-being. *Supportive Care in Cancer*, 15(7), 807-818.
- Klassen, A. F., Raina, P., McIntosh, C., Sung, L. Klaassen, R. J., O'Donnell, M., Yanofsky, R., & Dix, D. (2011). Parents of children with cancer: Which factors explain differences in health-related quality of life. *International Journal of Cancer*, 129, 1190-1198.

- Koch, U., Harter, M., Jakob, U., Siegrist, B. (1996). Parental reactions to cancer in their children. In Cancer and the family (pp.). In L. Baider, & C. L. Cooper (Eds). Oxford, England: John Wiley & Sons.
- Kylma, J., & Juvakka, T. (2007). Hope in parents of adolescents with cancer: Factors endangering and engendering parental hope. *European Journal of Oncology Nursing*, 11(3), 262-271.
- Lackey, N. R. (2000). Concept clarification: Using the Norris Method in clinical research. In B. L. Rodgers & K. A. Knafl (Eds.), *Concept Development in Nursing: Foundations, Techniques, and Applications*. Philadelphia: Saunders.
- Larson, E. (1998). Reframing the meaning of disability to families: The embrace of paradox. *Social Science Medicine*, 47(7), 865-875.
- Lavee, Y., & Mey-Dan, M. (2003). Patterns of change in marital relationships among parents of children with cancer. *Health and Social Work*, 28, 255-263.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Liu, Y.-M., & Yeh, C. H. (2010). Pediatric oncology: The use of cluster analysis to examine maternal concerns. *Oncology Nursing Forum*, 37(4), 304-311.
- Lloyd, T. J., & Hastings, R. (2009). Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities. *Journal of Intellectual Disability Research*, 53(12), 957-968. doi: 10.11/j.1365-2788.2009.01206.x
- Long, K. A., & Marsland, A. L. (2011). Family adjustment to childhood cancer: A systematic review. *Clinical Child and Family Psychological Review*, 14, 57-88.

- McCoyd, J.L., & Kerson, T.S. (2006). Conducting intensive interviews using email: A serendipitous comparative opportunity. *Qualitative Social Work*, 5, 389 – 406.
- McGrath, P. (2000). Findings on the impact for childhood acute lymphoblastic leukemia on family relationships. *Child and Family Social Work*, 6(3), 229-237.
- McGrath, P. (2001). Findings on the impact for childhood acute lymphoblastic leukemia on family relationships. *Child and Family Social Work*, 6(3), 229-237. doi: 10.1046/j.1365-2206.2001.00200.x
- McGrath, P. (2002). Beginning treatment for childhood acute lymphoblastic leukemia: Insights from the parents' perspective. *Oncology Nursing Forum*, 29(6), 988-996.
- McGrath, LP., Paton, M. A., & Huff, N. (2005). Beginning treatment for pediatric acute myeloid leukemia: The family connection. *Issues in Comprehensive Pediatric Nursing*, 28, 97-114.
- Mednick, L., Cogen, F., Henderson, C., Rohrbeck, C. A., Kitessa, D., & Streisand, R. (2007). Hope more, worry less: Hope as a potential resilience factor in mothers of very young children with Type 1 Diabetes. *Children's Health Care*, 36(4), 385-396.
- Meleis, A.I. (2007). *Theoretical nursing: Development and progress*. (4th Ed.). New York, NY: Lippincott, Williams, & Wilkins.
- Miedema, B., Hamilton, R., Fortin, P., Easley, J., & Matthews, M. (2010). "You can only take so much, and it took everything out of me": Coping strategies used by parents of children with cancer. *Palliative and Supportive Care*, 8, 197-206.
- Miller, J. F. (2007). Hope: A construct central to nursing. *Nursing Forum*, 42(1), 12-20.

- Monti, E. J., & Tingen, M. S. (1999). Multiple paradigms in nursing science. *Advances in Nursing Science, 21*(4), 64-80.
- Moore, J. B., & Mosher, R. B. (1997). Adjustment responses of children and their mothers to cancer: Self-care and anxiety. *Oncology Nursing, 24*(3), 519-536
- Morris, J. A., Blount, R. L., Cohen, L. C., Frank, N. C., Madan-Swain, A., & Brown, R. T. (1997). Family functioning and behavioral adjustment in children with leukemia and their healthy peers. *Children's Health Care, 26*, 61-75.
- Morse, J. (1994). *Critical Issues in Qualitative Research Methods*. Thousand Oaks, CA: Sage.
- Morse, J. M., & Doberneck, B. (1995). Delineating the concept of hope. *Image: Journal of Nursing Scholarship, 27*(4), 277-285.
- Morse, J. M., & Richards, L. (2002). *Readme First For a User's Guide to Qualitative Methods*. Thousand Oaks, Ca: Sage.
- Mu, P. F., Ma, F. C., Ku, S. M., Shu, H. Q., Hwang, B., & Kuo, B. I. (2001). Families of Chinese children with malignancy. The factors impact on mother's anxiety. *Journal of pediatric Nursing, 16*(4), 287-295.
- Neil-Urban, S., & Jones, J. B. (2002). Father-to-father support: fathers of children with cancer share their experiences. *Journal of Pediatric Oncology Nursing, 19*(3), 97-103.
- Nekolaichuk, C. L., Jevne, R. F., & Maguire, T. O. (1999). Structuring the meaning of hope in health and illness. *Social Science & Medicine, 48*(5), 591-605.
- Nicholas, D. B., Gearing, R. E., McNeill, T., Fung, K., Lucchetta, S., & Selkirk, E. K. (2009). Experiences and resistance strategies utilized by fathers of children with cancer. *Social Work in Health Care, 48*, 260-275.

- Norberg, A. L., Linblad, F. & Boman, K. K. (2005). Parental traumatic stress during and after paediatric cancer treatment. *Acta Oncologica*, 44, 382-388.
- Norberg, A. L., & Steneby, S. (2009). Experiences of parents of children surviving brain tumour: A happy ending with a rough beginning. *European Journal of Cancer Care*, 18, 371-380.
- Norris, C. M. (1982a). Concept Clarification: Approaches and Preliminaries. In C. M. Norris (Ed.), *Concept Clarification in Nursing* (pp. 21-35). Rockville, MD: Aspen.
- Norris, C. M. (1982b). *Concept Clarification in Nursing*. Rockville, MD: Aspen.
- Omery, A., Kasper, C. E., & Page, G. G. (Eds.). (1995). *In search of nursing science*. Thousand Oaks, CA: Sage.
- Padencheri, S., & Russell, P. S. (2002). Challenging behaviours among children with intellectual disability: The hope busters? *Journal of Intellectual Disabilities*, 6(3), 253-261. doi: 10.1177/1469004702006003035
- Pai, A. L., Greenly, R. F., Lewandowski, A., Drotar, D., Youngstrom, E., & Peterson, C.C. (2007). A meta-analytic review of the influence of pediatric cancer on parent and family functioning. *Journal of Family Psychology*, 21(3), 407-415.
- Patistea, E. (2000). Greek parents' reactions, difficulties and resources in childhood leukemia at the time of diagnosis. *European Journal of Cancer Care*, 9, 86-96.
- Patistea, E. (2005). Description and adequacy of parental coping behaviours in childhood leukemia. *International Journal of Nursing Studies*, 42, 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, 397-407.

- Polit, D. F., & Beck, C. T. (2008). *Nursing research: Generating and assessing evidence for nursing practice* (8th ed.). New York: Wolters Kluwer/Lippincott, Williams, & Wilkins.
- Polkinghorne, D. E. (1988). *Narrative knowing and the human sciences*. Albany, NY: State University of New York Press.
- Rawnsley, M. M. (2003). Dimensions of scholarship and the advancement of nursing science: Articulating a vision. *Nursing Science Quarterly*, *16*(1), 6-13.
doi:10.1177/0894318402239058
- Reder, E. A., & Serwint, J. R. (2009). Until the last breath. Exploring the concept of hope for parents and health care professionals during a child's serious illness. *Archives of Pediatrics & Adolescent Medicine*, *163*(7), 653-657.
- Reed, P. G. (2000). Nursing reformation: Historical reflections and philosophical foundations. *Nursing Science Quarterly*, *13*(2), 129-136. doi:10.1177/08943180022107564
- Riessman, C. K. (2008). *Narrative methods for the human sciences*. Thousand Oaks, CA: Sage.
- Robinson, K. E., Gerhardt, C. A., Vannatta, K., & Noll, R. B. (2007). Parent and family factors associated with child adjustment to childhood cancer. *Journal of Pediatric Psychology*, *32*, 400-410.
- Salmon, P., Hill, J., Ward, J., Gravenhorst, K., Eden, T., & Young, B. (2012). Faith and protection: The construction of hope by parents of children with leukemia and their oncologists. *The Oncologist*, *17*, 398-404.
- Samson, A., Tomiak, E., Dimillo, J., Lavigne, R., Miles, S., Choquette, M., Chakraborty, P., & Jacob, P. (2009). The lived experience of hope among parents of a child with Duchenne

- Muscular Dystrophy: Perceiving the human being beyond illness. *Chronic Illness*, 5(2), 103-114.
- Santacroce, S. (2002). Uncertainty, anxiety and symptoms of posttraumatic stress in parents of children recently diagnosed with cancer. *Journal of Pediatric Oncology Nursing*, 19(3), 104-111.
- Sawyer, M., Antoniou, G., Toogood, I., Rice, M., & Baghurst, P. (2000). Childhood Cancer: A 4-Year Prospective Study of the Psychological Adjustment of Children and Parents. *Journal of Pediatric Hematology/Oncology*, 22(3), 214-220.
- Sloper, P. (1996). Needs and responses of parents following the diagnosis of childhood cancer. *Child: Care, Health and Development*, 22(3), 187-202.
- Sloper, P. (2000). Predictors of distress in parents of children with cancer: A prospective study. *Journal of Pediatric Psychology*, 25(2), 79-91.
- Smith, A. W., Baum, A., & Wing, R. R. (2005). Stress and weight gain in parents of cancer patients. *International Journal of Obesity*, 29, 244-250.
- Snyder, C. R. (2000). Genesis: Birth and growth of hope. In C. R. Snyder (Ed.), *Handbook of hope: Theory, measures, and applications* (p. 25). San Diego, CA: Academic Press.
- Snyder, CR, Irving, LM, & Anderson, J. (1991). Hope and health. In CR Snyder & DR Forsyth (Eds.), *Handbook of social and clinical psychology: The health perspective* (pp. 285-305). Elmsford, NY: Pergamon Press.
- Strauss, A. L., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.

- Strauss, A. L., & Corbin, J. M. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage.
- Streisand, R., Kazak, A. E., & Tercyak, K. P. (2003). Pediatric specific parenting stress and family functioning in parents of children treated for cancer. *Children's Health Care*, 32, 245-256.
- Stephenson, C. (1991). The concept of hope revisited for nursing. *Journal of Advanced Nursing*, 16(12), 1456-1461.
- Sturges, J.E., & Hanrahan, K.J. (2004). Comparing telephone and face-to-face qualitative interviewing: A research note. *Qualitative Research*, 4, 107–118.
- Svavarsdottir, E. K. (2005). Caring for a child with cancer: a longitudinal perspective. *Journal*
- Sweet, L. (2002). Telephone interviewing: Is it compatible with interpretive phenomenological research? *Contemporary Nurse*, 12, 58–63.
- Tarr, J., & Pickler, R. H. (1999). Becoming a cancer patient: A study of families of children with acute lymphocytic leukemia. *Journal of Pediatric Oncology Nursing*, 16(1), 44-50.
- Taylor, J. D. (2000). Confronting breast cancer: Hopes for health. In C. R. Snyder (Ed.), *Handbook of hope: Theory, measures, and applications* (p. 368). San Diego, CA: Academic Press.
- Thampanichawat, W. (2008). Maintaining love and hope: Caregiving for Thai children with HIV infection. *Journal of the Association of Nurses in Aids Care*, 19(3), 200-210.
- Thomas, J. (1993). *Doing critical ethnography*. Newbury Park, CA: SAGE.
- Thomas-MacLean, R. (2004). Understanding breast cancer stories via Frank's narrative types. *Social Science & Medicine*, 58(9), 1647-1657.

- Venning, A. J., Elliott, J., Whitford, H., & Honnor, J. (2007). The impact of a child's chronic illness on hopeful thinking in children and parents. *Journal of Social and Clinical Psychology, 26*(6), 708-727.
- Vrijmoet-Wiersma, C.M., van Klink, J. M., Kolk, A.M., Koopman, H. M., Ball, L.M., & Egeler, R. M. (2008). Assessment of parental psychological stress in pediatric cancer: A review. *Journal of Pediatric Psychology, 33*(7), 694-706.
- Vroman, Warner & Chamberlain, K. (2009). Now let me tell you in my own words: narratives of acute and chronic low back pain. *Disability and Rehabilitation, 31*(12), 976-987.
- Wakefield, C. E., McLoone, J., Goodenough, B., Lenthen, K., Cairns, D. R., & Cohn, R. J. (2009). The Psychosocial Impact of Completing Childhood Cancer Treatment: A Systematic Review of the Literature. *Journal of Pediatric Psychology, 35*(3), 262-274.
- Weaver, K., & Olson, J. K. (2006). Understanding paradigms used for nursing research. *Journal of Advanced Nursing, 53*(4), 459-469. doi: 10.1111/j.1365-2648.2006.03740.x
- Whitehead, L. C. (2006). Quest, chaos, and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis. *Social Science & Medicine, 62*(9), 2236-2245.
- Wong, M. Y-F., & Chan, S. W-C. (2006). The qualitative experience of Chinese parents with children diagnosed of cancer. *Journal of Clinical Nursing, 15*, 710-717.
- Woodgate, R. L., & Degner, L. F. (2002). "Nothing is carved in stone!": Uncertainty in children with cancer and their families. *European Journal of Oncology Nursing, 6*(4), 191-202.
- Woodgate, R. L., & Degner, L. F. (2003). A substantive theory of keeping the spirit alive: The spirit within children with cancer and their families. *Journal of Pediatric Oncology Nursing, 20*, 103-119.

World Health Organization. (1998). *Cancer pain relief and palliative care in children*. Geneva:
Author.

Yates, P. (1993). Towards a reconceptualization of hope for patients with a diagnosis of cancer.
Journal of Advanced Nursing, 18(5), 701-706.

Yeh, C. (2002). Gender differences of parental distress in children with cancer. *Journal of
Advanced Nursing*, 38(6), 598-606.

Appendix A Ethical Approval



UNIVERSITY OF
SASKATCHEWAN

Behavioural Research Ethics Board (Beh-REB)

Certificate of Approval

PRINCIPAL INVESTIGATOR
Wendy D. Duggleby

DEPARTMENT
Nursing

BEH#
11-157

INSTITUTION(S) WHERE RESEARCH WILL BE CONDUCTED
University of Saskatchewan

SUB-INVESTIGATOR(S)
Lorraine Holtslander

STUDENT RESEARCHER(S)
Jill M.G. Bally

FUNDER(S)
INTERNALLY FUNDED

TITLE
The Hope Experience of Parental Caregivers of Children Undergoing Cancer Treatment

ORIGINAL REVIEW DATE
14-Jun-2011

APPROVAL ON
20-Jul-2011

APPROVAL OF:
Ethics Application
Consent Protocol

EXPIRY DATE
19-Jul-2012

Full Board Meeting

Date of Full Board Meeting:

Delegated Review

CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.usask.ca/research/ethics_review/

John Rigby, Chair
University of Saskatchewan
Behavioural Research Ethics Board

Please send all correspondence to:

Research Ethics Office
University of Saskatchewan
Box 5000 RPO University, 1602-110 Gymnasium Place
Saskatoon SK S7N 4J8
Telephone: (306) 966-2975 Fax: (306) 966-2069

Appendix B Supporting Letter

March 28, 2011

Re: *The Hope Experience of Parental Caregivers of Children Undergoing Cancer Treatment* (research proposal).

To Whom it May Concern,

I am pleased to write this letter of support for the research study titled *The Hope Experience of Parental Caregivers of Children Undergoing Cancer Treatment* proposed by Jill Bally, a PhD candidate.

Thorough attention has been paid to the understanding of the biology, medical management, and risk factors associated with pediatric cancers. However, the psychological impact on those diagnosed with cancer and their families, despite our awareness and its significant importance, has not been given the same attention. Particularly, the importance of hope as an important and effective resource for parents of children who have cancer, has been overlooked.

The proposed research project is important because of its potential impact on the care that is received by families, particularly parents who are the primary care providers for their children with cancer. It is likely that this research can aid in improving the psychological, social, and spiritual parameters of parental health by understanding, supporting, and enhancing their hope. In turn, parental physical health and caregiving abilities will also be supported and improved.

I am pleased to offer support and my collaborative efforts in relation to participant recruitment, and any other avenues that may be indicated as the study progresses.

I have no hesitation in strongly supporting this research project and I am pleased to do so.

Sincerely,

Chris Mpofu MBChB, MSc, FRCP(C)
Pediatric Oncologist
Saskatoon Cancer Centre
20 Campus Drive
Saskatoon, SK, S7N 4H4

Appendix C Letter for Those Assisting with Recruitment

Dear (name to be inserted),

Thanks so much for agreeing to assist with my research project by taking the time to speak to potential families about my study titled *The Experience of Hope for Parental Caregivers of Children Undergoing Cancer Treatment*. Your time and input are valuable and appreciated.

I am seeking to understand the hope experience of parents who are primary caregivers for their children who have cancer. Therefore, I am asking for your assistance in identifying parents from across Saskatchewan who are the primary caregivers for their child aged birth to 12 years of age who are undergoing cancer treatment and who are willing to participate in this study. Participation will require an initial face to face interview focused on discussing their hope as they care for their child, the completion of a journal over two weeks, and a follow up interview by telephone. In total, I anticipate that the time involved for participation will be about 3-4 hours over a period of two weeks.

Below, I have listed the inclusion criteria to which you may refer in order to identify those parents who will be suitable. If the parent is willing to talk further about the study, you can ask them if I can contact them, and obtain their contact information (telephone number and full name). You can then send me the parent's names and contact information at jill.bally@usask.ca, or by telephone at 343 9355. I will then contact each parent and provide more information regarding their potential participation in the study. In total, I anticipate that I will require approximately 25 participants.

Inclusion criteria for my study are provided so that you can determine which parents will be eligible participants:

- Parents of children between birth – 12 years of age who have been diagnosed with cancer and are undergoing treatment for cancer, are within approximately 12 months since diagnosis, and who are the primary caregiver for their child. (For example, a mother or father who stays home with the child, is mainly the parent who attends appointments, stays with child in hospital, and so on.)
- A Parent who lives anywhere in Saskatchewan and whose child receives care through the Saskatoon Cancer Centre
- A Parent who is willing to participate, speaks English, and who is able to consent freely

The proposed research study will enhance the understanding of the personal and unique hope experiences of parents who have children with cancer. This information may help to improve the care that such parents receive as they parent their children who are undergoing cancer treatment. In addition, parents may find it helpful to talk about their hope and to contribute to our understanding of their very important perspective as it relates to their own health and well-being.

Thank you once again for your willingness to assist me in undertaking this research project. I appreciate your time and look forward to collaborating with you as this study progresses. If you have any questions or comments at any time, please feel welcome to contact me.

Sincerely,

Jill M. G. Bally RN, PhD (c)

Appendix D
Letter of Introduction for Potential Participants

Study Title: *The Experience of Hope for Parental Caregivers of Children Undergoing Cancer Treatment*

Dear Parent,

My name is Jill Bally and I am a doctoral candidate in the College of Nursing at the University of Saskatchewan. I am conducting a research study as part of the requirements of my doctoral degree in nursing, and I would like to invite you to participate.

I am studying hope as it relates to your experience as a parent with a child who has cancer in order to gain a better understanding of it and then describe your hope experiences. I have had the privilege of working with many children and families who have been admitted to the acute care pediatric setting for health care related to their child's diagnosis of cancer. This has touched me on many levels and I have experienced the need for more effective and informed family support for families such as yours. There is very little research in this area to date, and I believe that your personal experiences will contribute to a better understanding of the issues that families face, and to the development of quality, family centered health care. I know that your experiences and perceptions of hope are key to this understanding, and therefore, I am asking for your participation.

If you decide to participate, you will be asked to meet with me for an interview to talk about your hope as you provide care for your child.

In particular, we will discuss a few questions that focus on your hope. The meeting will take place in your home, or a mutually agreed upon place that is convenient for you and should last about one hour. After our initial meeting I would also ask that you take a few minutes each day to write in a journal to document your thoughts and feelings related to your hope. I would then like to meet with you a second time via telephone to follow up with our first conversation and your journal. The interviews will be audio taped so that I can accurately reflect on what is discussed. The tapes will be reviewed by members of the research team only. They will then be destroyed. I propose that the time required to participate will be about 3-4 hours over a period of two weeks.

You may feel uncomfortable answering some of the questions, but you do not have to answer any questions that you do not wish to. Although you may not benefit directly from participating in this study, we hope that parents like yourself may benefit by the understanding that is gained through your experiences. Some participants have found it helpful to discuss their hope and some have found benefit in helping others through sharing their own experiences.

Participation is confidential. Study information will be kept in a secure location at the University of Saskatchewan, College of Nursing. The results of the study may be published or presented at professional meetings, but your identity will not be revealed.

Taking part in the study is your decision. You do not have to be in this study if you do not want to be. You may also quit being in the study at any time or decide not to answer any question you are not comfortable answering.

We will be happy to answer any questions you have about the study. You may contact me (Jill Bally at 343 9355, jill.bally@usask.ca) or my faculty advisors, (Dr. Wendy Duggleby at 780-492-8660, wendy.duggleby@ualberta.ca; Dr. Lorraine Holtslander at 966 8204, lorraine.holtslander@usask.ca) if you have study related questions or comments. If you have any questions about your rights as a research participant, you may contact the Research Ethics Office at the University of Saskatchewan at 306-966-4053.

If you think this is something in which you would like to participate, please contact me at the number listed below to discuss your participation. Alternatively, you can provide the staff member who provided you with information on the study with your contact information and I will call you within a week to provide you with more information. At that time, if you are not interested in participating, you will not be under any obligation to do so.

Thank you for your consideration.

With kind regards,

Jill M. G. Bally
343 9355
jill.bally@usask.ca

Appendix E Consent Form

You are invited to participate in a research project entitled: *The Experience of Hope for Parental Caregivers of Children Undergoing Cancer Treatment*. Please read this form carefully, and feel free to ask questions you might have.

Researchers:

Jill Bally, RN, MN, PhD(c), College of Nursing, University of Saskatchewan, Saskatoon, SK, Phone: 306 3439355

Dr. Wendy Duggleby, RN, DSN, AOCN, Co-Supervisor of Student, Faculty of Nursing University of Alberta, Edmonton, Alberta, Phone: 780-492-8660

Dr. Lorraine Holtlander, RN, MN, PhD, Co-Supervisor of Student, Faculty of Nursing, University of Saskatchewan, Saskatoon, SK, Phone: 966-8204

Purpose and Procedure: The purpose of this study is to find out what hope means for you, as a parent and caregiver, during the time that your child has been in treatment for childhood cancer. Nurses and other health care workers can benefit from learning about the hope of parents who care for their children during cancer treatment so that they can better support other families in similar situations.

My name is Jill Bally, and I am a Registered Nurse who has worked in Pediatrics for a number of years. My interest in this research stems in part from my current goal to pursue PhD studies. More importantly, I have had the privilege of working with many children and families who have been admitted to the acute care pediatric setting for health care related to their child's diagnosis of cancer. This has touched me on many levels and I have experienced the need for more effective and informed family centered nursing care for families such as yours. There is very little research in this area to date, and I believe that your personal experiences will contribute to a better understanding of the issues that families face, and to the development of quality, family centered health care. I know that your experiences and perceptions of hope are key to this understanding, and therefore, I am asking for your participation.

I would like to interview you at a time that you find agreeable. If you agree to participate, I will visit you in your home, or at a location of your choice when it is convenient for you. You will be asked to answer questions about yourself (gender, age, etc.) and questions such as the age, and diagnosis of your child. Then you will be asked questions about hope. With your permission, our discussion will be audio taped. This interview will take approximately one hour. I would like to talk with you again at a time that is best for you, about two weeks after our first meeting by telephone. I will use this time to answer any of your questions, to verify my understanding of our first discussion, and to address any questions that may arise. The second interview should take approximately 30 – 45 minutes.

I would also like you to keep a brief daily journal (you may write for about five minutes each day) over a two-week period. You can address any thoughts or feelings that you have regarding hope in general, and a guideline will be provided that you may chose to follow. If you prefer, I can provide you with a tape recorder that you may use instead of writing a journal, to record your

entries. With your permission, I would like to photocopy the journal and include this information in the data analysis. During our second visit, we can talk about your journals, as you wish. I anticipate that the total time of your involvement in this study may be about three to four hours (about one hour for each of the two visits, and time to write in your journal over a two week period of time).

Potential Benefits: Taking part in this study may not benefit you directly. Some people have found it helpful to talk about their situation and concerns with a Registered Nurse. The information that you provide may be of help to others. This information will be used by health care professionals to provide improved and more effective health care for families in similar situations.

Potential Risks: Answering the questions during the interview may be tiring. You do not have to answer any questions that you do not want to answer and you can terminate your involvement in the study at any time, as you wish. If you get tired, or you feel upset, you can take a break at any time, or end the interview. If you wish, I will call your family doctor, and, or some one of support to you, on your behalf.

Storage of Data: Your answers to the questions and copies of your journal entries will be stored in a locked drawer at the College of Nursing, for at least five years. Only the research team will be able to look at this information.

Confidentiality: Your answers to the questions will be written on a form that will not have your name on it. The tape recordings of our discussions will be transcribed, but your name will not be on any of the information. Your written journals will be photocopied and, or transcribed, any personal information removed, and the original document will be returned to you. The consent forms and demographic forms will be stored separately from your answers. All information from this study will be reported in a group format for conferences and publications so that no one can identify you. Although direct quotations will be used in reporting the results of this study, they will be presented in such a way so as to ensure that no one can identify you. Your name will not be used, and all identifying information will be removed from the report.

Right to Withdraw: Your participation is voluntary, and you may answer only those questions with which you are comfortable. There is no guarantee that you will personally benefit from your involvement. The information that is shared will be held in strict confidence and discussed only with the research team. You may withdraw from the research project for any reason, at any time, without penalty of any sort. You may withdraw by notifying me at any time. Withdrawing from this study at any point in time, will not affect your care, or the care that your child receives in any way. If you withdraw from the research project at any time, any data that you have contributed will be destroyed at your request.

Questions: If you have any questions concerning the research project, please feel free to ask at any point. You are also free to contact the researchers at the numbers provided if you have other questions. This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on ([will insert date](#)). Any questions regarding

your rights as a participant may be addressed to that committee through the Ethics Office (966-2084). Out of town participants may call collect.

Follow-Up or Debriefing: You may find out about the results of this research project by contacting me at any time.

Consent to Participate:

(a) Written Consent

I have read and understood the description provided. I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project, understanding that I may withdraw my consent at any time. A copy of this Consent Form has been given to me for my records.

_____	_____
(Name of Participant)	(Date)
_____	_____
(Signature of Participant)	(Signature of Researcher)

Appendix F
Data Collection Tools: Demographic Form

The Experience of Hope for Parental Caregivers of Children Undergoing Cancer Treatment
Demographic Form

Date: _____ Code Number: _____

A. Participant (Caregiver Information)

Age: _____ Gender: _____ Years of Education: _____

Marital Status: M S W D Religious Preference: _____

Occupation: _____ Ethnicity: _____

Medical Information: (General Health) _____

Current Medications: _____

Other Children: _____

B. Pediatric Client

Age: _____ Gender: _____

Medical Diagnosis: _____

Date of Diagnosis: _____

Date of Onset of Treatment: _____

Expected Length of Treatment: _____

Type of Treatment: _____

Current Health Issues/Concerns: _____

Appendix G

Data Collection Tools: The Interview Guide

Introduction to Interview

Thank you for agreeing to be interviewed today. I am meeting with you to learn more about your experience in providing care for your child and what that means in relation to your hope. There are no right or wrong answers to the questions that I ask, and what I hope to gain is knowledge about your experience, through your eyes. Through our discussion today, I hope to get a better understanding of your experience. Do you have any questions before we begin?

Interview Guide

- Can you tell me about the time around the diagnosis of your child?
- Hope seems to be a part of many cancer experiences. What is hope like for you?
 - **Prompt:** Can you tell me a little bit more about hope? What does it mean for you?
 - **Prompt:** Can you define hope?
- What does hope look like? What does hope feel like?
- Have you noticed any changes in your hope since the time your child was diagnosed with cancer up until today?
 - **Prompt:** Can you describe those changes?
 - **Prompt:** How might changes in the health of your child affect the way in which you would describe hope? How did you feel during this time? What were your thoughts?
- Can you describe situations that affect your hope positively, or increase it?
- Can you tell me about situations that affect your hope negatively, or decrease it?

Is there anything that I have not asked you that you would like to add?

Is there anything that you would like to ask me?

What has it been like for you to discuss your hope?

Appendix H

Data Collection Tools: A Guide to Keeping a Hope Journal

Thank you for agreeing to keep a daily journal related to your hope experiences. The notes that you provide will assist me in understanding your hope experiences on a day to day basis over the next two weeks. You may begin your journal following our first interview and continue for 10-14 days.

Try to write in your journal for about 5-10 minutes each day with the goal being a personal reflection on your day. You can write as much or as little as you wish and you needn't worry about your writing style, spelling, or grammar. Feel free to write in point form. Please do not feel obligated to write in your journal if you are too tired, or if it inconveniences you in any way.

Below are a few ideas to get you started, or you may use these ideas to frame your daily entries, adding what you like to provide an understanding of your daily hope experiences.

- Record your general thoughts, feelings and experiences related to hope
- What/who influenced your hope today?
- Were there any specific actions, supports, or activities that enhanced your hope today?
- Did hope effect the way that you cared for, or related to your child?
- How did hope influence your interactions with others today?

**Appendix I
Research Brochure for Participants**



This research project has received ethical approval through the University of Saskatchewan Research Ethics Board and the Saskatoon Cancer Centre. Any questions regarding your rights as a participant may be addressed through the Ethics Office (966-2084). Out of town participants may call collect.



**Contact
Jill Bally**

If you are interested in participating in this study please contact Jill Bally at any time.

Thank you for your consideration.



Jill Bally

1 306 281 4373

jill.bally@usask.ca



Hope



*The Hope
Experience of
Parental
Caregivers of
Children
Undergoing
Cancer Treatment*





UNIVERSITY OF
SASKATCHEWAN

College of Nursing

The Hope Experience of Parental Caregivers of Children Undergoing Cancer Treatment

The purpose of this study is to find out what hope means for you during the time that your child is in treatment for childhood cancer.

By participating in this study you may not experience any personal benefits, although many participants who talk about their hope find it to be informative and helpful. Your participation may assist nurses and other health care workers to learn more about the hope of parents who care for their children during cancer treatment so that they can better support other families in similar situations.

Prior to beginning the study, you will also be asked to read and sign a consent form and complete a form that asks general information about you, such as occupation, education, and age. A copy of the consent form will be given to you for your records.

If you choose to participate you will be asked to talk with me on two or three different occasions and to write in a diary over a two week period. The conversations will be audiotaped and the journals will be photocopied. Your time commitment will be approximately 3-4 hours in total. Your confidentiality will be maintained at all times.

Your participation is voluntary and you may choose to withdraw from this research study at any time without penalty by contacting me at the number or email address provided. No questions will be asked.

THANK YOU FOR YOUR INTEREST

A...

Q & A

Who is the researcher?

Jill Bally, RN, MN, PhD(c),
College of Nursing, University
of Saskatchewan, Saskatoon,
SK, Phone: 306 281 4373

Who is supervising the research?

Dr. Wendy Duggleby, RN,
DSN, AOCN, Faculty of
Nursing University of Alberta,
Edmonton, Alberta, Phone:
780-492-8660

Dr. Lorraine Holtlander,
RN, MN, PhD, Faculty of
Nursing, University of
Saskatchewan, Saskatoon, SK,
Phone: 966-8204

Why is this important?

Hope is an important aspect of health and illness. The information that you provide will help us to understand your hope more fully. With a better understanding of the hope of parents, health care providers would be better equipped to support your hope.

A...

Appendix J

Letter of Permission to Include Published Manuscript in Dissertation

Rightslink Printable License

12-09-14 12:31 PM

JOHN WILEY AND SONS LICENSE TERMS AND CONDITIONS

Sep 14, 2012

This is a License Agreement between Jill bally ("You") and John Wiley and Sons ("John Wiley and Sons") provided by Copyright Clearance Center ("CCC"). The license consists of your order details, the terms and conditions provided by John Wiley and Sons, and the payment terms and conditions.

All payments must be made in full to CCC. For payment instructions, please see information listed at the bottom of this form.

License Number	2987770299015
License date	Sep 14, 2012
Licensed content publisher	John Wiley and Sons
Licensed content publication	Journal for Specialists in Pediatric Nursing
Licensed content title	Viewing the art and the science of pediatric nursing through the lens of paradigms: The impact on hope for the future
Licensed content author	Jill M. G. Bally
Licensed content date	Apr 4, 2012
Start page	215
End page	225
Type of use	Dissertation/Thesis
Requestor type	Author of this Wiley article
Format	Print and electronic
Portion	Full article
Will you be translating?	No
Order reference number	
Total	0.00 USD

Terms and Conditions

TERMS AND CONDITIONS

This copyrighted material is owned by or exclusively licensed to John Wiley & Sons, Inc. or one of its group companies (each a "Wiley Company") or a society for whom a Wiley Company has exclusive publishing rights in relation to a particular journal (collectively WILEY"). By clicking "accept" in connection with completing this licensing transaction, you agree that the following terms and conditions apply to this transaction (along with the billing and payment terms and conditions established by the Copyright Clearance Center Inc., ("CCC's Billing and Payment terms and conditions"), at the time that you opened your Rightslink account (these are available at any time at <http://myaccount.copyright.com>)

Terms and Conditions

1. The materials you have requested permission to reproduce (the "Materials") are protected by copyright.
2. You are hereby granted a personal, non-exclusive, non-sublicensable, non-transferable, worldwide, limited license to reproduce the Materials for the purpose specified in the licensing process. This license is for a one-time use only with a maximum distribution equal to the number that you identified in the licensing process. Any form of republication granted by this licence must be completed within two years of the date of the grant of this licence (although copies prepared before may be distributed thereafter). The Materials shall not be used in any other manner or for any other purpose. Permission is granted subject to an appropriate acknowledgement given to the author, title of the material/book/journal and the publisher. You shall also duplicate the copyright notice that appears in the Wiley publication in your use of the Material. Permission is also granted on the understanding that nowhere in the text is a previously published source acknowledged for all or part of this Material. Any third party material is expressly excluded from this permission.
3. With respect to the Materials, all rights are reserved. Except as expressly granted by the terms of the license, no part of the Materials may be copied, modified, adapted (except for minor reformatting required by the new Publication), translated, reproduced, transferred or redistributed, in any form or by any means, and no derivative works may be made based on the Materials without the prior permission of the respective copyright owner. You may not alter, remove or suppress in any manner any copyright, trademark or other notices displayed by the Materials. You may not license, rent, sell, loan, lease, pledge, offer as security, transfer or assign the Materials, or any of the rights granted to you hereunder to any other person.
4. The Materials and all of the intellectual property rights therein shall at all times remain the exclusive property of John Wiley & Sons Inc or one of its related companies (WILEY) or their respective licensors, and your interest therein is only that of having possession of and the right to reproduce the Materials pursuant to Section 2 herein during the continuance of this Agreement. You agree that you own no right, title or interest in or to the Materials or any of the intellectual property rights therein. You shall have no rights hereunder other than the license as provided for above in Section 2. No right, license or interest to any trademark, trade name, service mark or other branding ("Marks") of WILEY or its licensors is granted hereunder, and you agree that you shall not assert any such right, license or interest with respect thereto.
5. NEITHER WILEY NOR ITS LICENSORS MAKES ANY WARRANTY OR REPRESENTATION OF ANY KIND TO YOU OR ANY THIRD PARTY, EXPRESS, IMPLIED OR STATUTORY, WITH RESPECT TO THE MATERIALS OR THE ACCURACY OF ANY INFORMATION CONTAINED IN THE MATERIALS, INCLUDING, WITHOUT LIMITATION, ANY IMPLIED WARRANTY OF MERCHANTABILITY, ACCURACY, SATISFACTORY QUALITY, FITNESS FOR A PARTICULAR PURPOSE, USABILITY, INTEGRATION OR NON-INFRINGEMENT AND ALL SUCH WARRANTIES ARE HEREBY EXCLUDED BY WILEY AND ITS LICENSORS AND WAIVED BY YOU.
6. WILEY shall have the right to terminate this Agreement immediately upon breach of this Agreement by you.
7. You shall indemnify, defend and hold harmless WILEY, its Licensors and their respective directors, officers, agents and employees, from and against any actual or threatened claims, demands, causes of action or proceedings arising from any breach of this Agreement by you.
8. IN NO EVENT SHALL WILEY OR ITS LICENSORS BE LIABLE TO YOU OR ANY OTHER PARTY OR ANY OTHER PERSON OR ENTITY FOR ANY SPECIAL, CONSEQUENTIAL, INCIDENTAL, INDIRECT, EXEMPLARY OR PUNITIVE DAMAGES, HOWEVER CAUSED, ARISING OUT OF OR IN CONNECTION WITH THE DOWNLOADING, PROVISIONING, VIEWING OR USE OF THE MATERIALS REGARDLESS OF THE FORM OF ACTION, WHETHER FOR BREACH OF CONTRACT, BREACH OF WARRANTY, TORT, NEGLIGENCE, INFRINGEMENT OR OTHERWISE (INCLUDING, WITHOUT LIMITATION,

DAMAGES BASED ON LOSS OF PROFITS, DATA, FILES, USE, BUSINESS OPPORTUNITY OR CLAIMS OF THIRD PARTIES), AND WHETHER OR NOT THE PARTY HAS BEEN ADVISED OF THE POSSIBILITY OF SUCH DAMAGES. THIS LIMITATION SHALL APPLY NOTWITHSTANDING ANY FAILURE OF ESSENTIAL PURPOSE OF ANY LIMITED REMEDY PROVIDED HEREIN.

9. Should any provision of this Agreement be held by a court of competent jurisdiction to be illegal, invalid, or unenforceable, that provision shall be deemed amended to achieve as nearly as possible the same economic effect as the original provision, and the legality, validity and enforceability of the remaining provisions of this Agreement shall not be affected or impaired thereby.

10. The failure of either party to enforce any term or condition of this Agreement shall not constitute a waiver of either party's right to enforce each and every term and condition of this Agreement. No breach under this agreement shall be deemed waived or excused by either party unless such waiver or consent is in writing signed by the party granting such waiver or consent. The waiver by or consent of a party to a breach of any provision of this Agreement shall not operate or be construed as a waiver of or consent to any other or subsequent breach by such other party.

11. This Agreement may not be assigned (including by operation of law or otherwise) by you without WILEY's prior written consent.

12. Any fee required for this permission shall be non-refundable after thirty (30) days from receipt.

13. These terms and conditions together with CCC's Billing and Payment terms and conditions (which are incorporated herein) form the entire agreement between you and WILEY concerning this licensing transaction and (in the absence of fraud) supersedes all prior agreements and representations of the parties, oral or written. This Agreement may not be amended except in writing signed by both parties. This Agreement shall be binding upon and inure to the benefit of the parties' successors, legal representatives, and authorized assigns.

14. In the event of any conflict between your obligations established by these terms and conditions and those established by CCC's Billing and Payment terms and conditions, these terms and conditions shall prevail.

15. WILEY expressly reserves all rights not specifically granted in the combination of (i) the license details provided by you and accepted in the course of this licensing transaction, (ii) these terms and conditions and (iii) CCC's Billing and Payment terms and conditions.

16. This Agreement will be void if the Type of Use, Format, Circulation, or Requestor Type was misrepresented during the licensing process.

17. This Agreement shall be governed by and construed in accordance with the laws of the State of New York, USA, without regards to such state's conflict of law rules. Any legal action, suit or proceeding arising out of or relating to these Terms and Conditions or the breach thereof shall be instituted in a court of competent jurisdiction in New York County in the State of New York in the United States of America and each party hereby consents and submits to the personal jurisdiction of such court, waives any objection to venue in such court and consents to service of process by registered or certified mail, return receipt requested, at the last known address of such party.

Wiley Open Access Terms and Conditions

All research articles published in Wiley Open Access journals are fully open access: immediately freely available to read, download and share. Articles are published under the terms of the [Creative Commons Attribution Non Commercial License](#), which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for

commercial purposes. The license is subject to the Wiley Open Access terms and conditions: Wiley Open Access articles are protected by copyright and are posted to repositories and websites in accordance with the terms of the [Creative Commons Attribution Non Commercial License](#). At the time of deposit, Wiley Open Access articles include all changes made during peer review, copyediting, and publishing. Repositories and websites that host the article are responsible for incorporating any publisher-supplied amendments or retractions issued subsequently. Wiley Open Access articles are also available without charge on Wiley's publishing platform, **Wiley Online Library** or any successor sites.

Use by non-commercial users

For non-commercial and non-promotional purposes individual users may access, download, copy, display and redistribute to colleagues Wiley Open Access articles, as well as adapt, translate, text- and data-mine the content subject to the following conditions:

- The authors' moral rights are not compromised. These rights include the right of "paternity" (also known as "attribution" - the right for the author to be identified as such) and "integrity" (the right for the author not to have the work altered in such a way that the author's reputation or integrity may be impugned).
- Where content in the article is identified as belonging to a third party, it is the obligation of the user to ensure that any reuse complies with the copyright policies of the owner of that content.
- If article content is copied, downloaded or otherwise reused for non-commercial research and education purposes, a link to the appropriate bibliographic citation (authors, journal, article title, volume, issue, page numbers, DOI and the link to the definitive published version on Wiley Online Library) should be maintained. Copyright notices and disclaimers must not be deleted.
- Any translations, for which a prior translation agreement with Wiley has not been agreed, must prominently display the statement: "This is an unofficial translation of an article that appeared in a Wiley publication. The publisher has not endorsed this translation."

Use by commercial "for-profit" organisations

Use of Wiley Open Access articles for commercial, promotional, or marketing purposes requires further explicit permission from Wiley and will be subject to a fee. Commercial purposes include:

- Copying or downloading of articles, or linking to such articles for further redistribution, sale or licensing;
- Copying, downloading or posting by a site or service that incorporates advertising with such content;
- The inclusion or incorporation of article content in other works or services (other than normal quotations with an appropriate citation) that is then available for sale or licensing, for a fee (for example, a compilation produced for marketing purposes, inclusion in a sales pack)
- Use of article content (other than normal quotations with appropriate citation) by for-profit organisations for promotional purposes
- Linking to article content in e-mails redistributed for promotional, marketing or educational purposes;

- Use for the purposes of monetary reward by means of sale, resale, licence, loan, transfer or other form of commercial exploitation such as marketing products
- Print reprints of Wiley Open Access articles can be purchased from:
corporatesales@wiley.com

Other Terms and Conditions:

BY CLICKING ON THE "I AGREE..." BOX, YOU ACKNOWLEDGE THAT YOU HAVE READ AND FULLY UNDERSTAND EACH OF THE SECTIONS OF AND PROVISIONS SET FORTH IN THIS AGREEMENT AND THAT YOU ARE IN AGREEMENT WITH AND ARE WILLING TO ACCEPT ALL OF YOUR OBLIGATIONS AS SET FORTH IN THIS AGREEMENT.

v1.7

If you would like to pay for this license now, please remit this license along with your payment made payable to "COPYRIGHT CLEARANCE CENTER" otherwise you will be invoiced within 48 hours of the license date. Payment should be in the form of a check or money order referencing your account number and this invoice number RLNK500857833.

Once you receive your invoice for this order, you may pay your invoice by credit card. Please follow instructions provided at that time.

**Make Payment To:
Copyright Clearance Center
Dept 001
P.O. Box 843006
Boston, MA 02284-3006**

For suggestions or comments regarding this order, contact RightsLink Customer Support: customercare@copyright.com or +1-877-622-5543 (toll free in the US) or +1-978-646-2777.

Gratis licenses (referencing \$0 in the Total field) are free. Please retain this printable license for your reference. No payment is required.
