THE EXPERIENCE OF HOPE

FOR INFORMAL CAREGIVERS

OF PALLIATIVE HOME CARE PATIENTS:

A GROUNDED THEORY EXPLORATION

A Thesis Submitted to the College of

Graduate Studies and Research

In Partial Fulfillment of the Requirements

For the Degree of Master of Nursing

In the College of Nursing

University of Saskatchewan

Saskatoon, Saskatchewan

By

Lorraine Holtslander

ABSTRACT

The purpose of this study was to explore the processes of hope in informal caregivers of palliative patients. Interviews were conducted with caregivers who were living with and currently providing care to a palliative patient at home. Saturation was reached with 10 caregivers, five females and five males, from 2 cities in Saskatchewan, Canada.

The design of this qualitative study was Glaser's (2001) grounded theory. Broad, unstructured face to face audio taped interviews were conducted in the participants' homes. Interviews were transcribed verbatim and analyzed using constant-comparative method of analysis in order to identify the main concern of the participants related to hope, and the basic social processes used to resolve that concern.

"Eroding hope" was the main concern relating to hope during caregiving for a palliative patient. Eroding hope was a result of bad days, negative messages, and experiences with the health care system. The participants deal with eroding hope by using the basic social process of "hanging on to hope." Hanging on to hope has 4 sub-processes: a)doing what you have to do, b)living in the moment, c)staying positive, and d)writing your own story. The support of friends, family, and health care professionals and connecting with something bigger and stronger were sub-processes of hanging on to hope that together directly affect the other sub-processes.

The findings of this study have direct application for the care and support of informal caregivers providing palliative care at home, as a basis for assessment and

interventions that will assist caregivers to hang on to hope. Nurses and other health care professionals need to recognize and value the experience of hope for caregivers by addressing, teaching, and reinforcing the sub-processes and ways of hanging on to hope into their practice.

LIST OF TABLES

LIST OF FIGURES

1   CHAPTER ONE - INTRODUCTION, BACKGROUND FOR THE STUDY, AND REVIEW OF THE LITERATURE

1.1   Introduction

Hope has been identified as a psychosocial resource used by informal caregivers of palliative patients to deal with a difficult, stressful, though significant caregiving experience (Borneman, Stahl, Ferrell, & Smith, 2002; Herth, 1993). Nurses are in an optimal position to promote and foster hope, supporting informal caregivers as they care for family members with a life-threatening condition:

> Nurses are the experts in the palliative care setting, where the goal is pain control and symptom management, but more important than that is addressing the issues of hope, the meaning of life, and making amends with family. Nurses have a major role to play in helping individuals and families address these issues in end-of-life care (R. Romanow, personal communication, October 31, 2003).

Little is known about the experience of hope for informal caregivers of palliative patients. What is their main concern related to hope? What are the basic social processes used by informal caregivers of palliative home care patients to resolve their main concern? The purpose of this research study was to examine the experience and processes of hope for informal caregivers of palliative home care patients, with the ultimate goal of providing more effective and compassionate nursing care to this population.

The goal of palliative care is to improve the quality of life for patients and families faced with a life-threatening illness, offering a support system to help the

family cope during the illness and in their time of bereavement (World Health Organization, 2003). Sensitivity to the physical, psychosocial, and spiritual concerns of patients and families are reflected in all aspects of palliative care. The proposed study will add a deeper understanding of the hope experience for informal caregivers of palliative patients, addressing the gap found in the research literature. By examining the concerns of caregivers related to hope, practitioners will be provided with effective tools to support caregivers through their journey. Ongoing practical tools, based on research, may be developed and enhanced to address the issue of hope for caregivers faced with a challenging life situation.

1.2   Relevance and Significance of the Study

Hope was found to be a recurring theme in the results of many research studies with palliative caregivers, even though hope was not identified as a research variable. For family members of palliative patients, hope was always present, whether for a miracle cure or in the preparation for death (Dawson & Kristjanson, 2003; Mok, Chan, Chan, & Yeung, 2003). Martens and Davies (1990) described "hoping" as a type of meaningful "work" requiring energy, focus, positive attitude, and faith. Maintaining hope was a strategy that enabled families to continue day to day (Yates & Stetz, 1999). For family members, "good" days were described as having hope and fulfillment. Lack of joy and hope were features of poor palliative care (Miettinin, Alaviuhkola, & Pietila, 2001).

In reviewing the literature on palliative caregivers, a trend can be seen in the shift from examining the burden of care to searching for the positive aspects of caregiving, such as finding meaning, using faith as a coping mechanism, and addressing

the spiritual aspects of care at the end of life. The previous research on palliative caregivers supports the need for an exploration of the experience and processes of hope as a valuable resource to support and assist informal caregivers giving palliative care.

Researchers exploring the demands and stresses of caregiving have described the multiple needs of palliative caregivers (Brown, Davies, & Martens, 1990; Chiverton, 1997; Enyert & Burman, 1999; Hudson, Aranda, & McMurray, 2002; Hudson, 2004; Hull, 1990; Mok et al., 2003; Proot, et al., 2003; Rose, 1998; Sherwood, Given, Doorenbos, & Given, 2004; Stajduhar & Davies, 1998; Stetz, 1987; Yates & Stetz, 1999). For caregivers, providing palliative care at home was described as a slow, distressing, and painful experience (Davis, Cowley, & Ryland, 1996). The concerns of caregivers included the patient's symptom distress (Kristjanson, Sloan, Dudgeon, & Adaskin, 1996), the complexities and uncertainties of their role, (Chiverton, 1997), and the significant personal cost involved (Aranda, 2001). Hudson (2004) found that 40% of palliative caregivers were unable to identify any positive aspects of caregiving. A review of these and other studies addressing caregivers in palliative care situations is contained in Appendix A.

The needs of palliative caregivers in Canada's health care system are not being adequately addressed. The Canadian health care system struggles to provide palliative care in the midst of health care restructuring and increasing costs and has become increasingly reliant on informal caregivers to provide care at home (Canadian Hospice Palliative Care Association, 2001). The resources available to support palliative care at home vary widely across Canada. The Commission on the Future of Health Care in Canada (2002) acknowledged the increasing burden on families to provide palliative

care and recommended the development of support programs for informal caregivers. Furthermore, the Canadian Palliative Care Association (1999) recommended increased research in the areas of existential and spiritual concerns to improve the effectiveness of support offered to caregivers.

An area of research that has not been adequately addressed is the experience and processes of hope for palliative caregivers. Hope is defined as a basic requirement of the human condition; consisting of an experiential process, a spiritual process, a rational thought process, and a relational process (Farran, Herth, & Popovich, 1995). Only three published research studies have specifically addressed hope in caregivers of palliative patients. In these three studies, hope was found to be an effective and powerful tool to facilitate coping and quality of life for caregivers (Borneman et al., 2002; Chapman & Pepler, 1998; Herth, 1993). The studies by Borneman, et al. and Herth were conducted in the United States. The Canadian study by Chapman and Pepler found positive correlations between hope and constructive coping in family members of palliative patients. Exploring the experience and processes of hope of Canadian palliative caregivers may provide insight and understanding for health care professionals in order to improve the support for these caregivers.

1.3 Conceptual Framework

As little is known about the complex construct of hope in palliative caregivers, a qualitative exploratory approach was used. Qualitative research locates the researcher in the world and uses interpretation to transform the world it examines (Denzin & Lincoln, 2000). Each type of qualitative research makes the world visible in a different way. Grounded theory research asks: "What is going on here?" as a starting point when little

is known or understood about the complex situation being examined (Morse & Richards, 2002). When doing grounded theory the researcher gathers data without forcing preconceived frameworks on it in order to generate theory that explains what is going on (Glaser, 2001).

Grounded theory has its origins in symbolic interactionism, that is, reality is always being negotiated between people, changing, and evolving. Social interaction is a process that forms human conduct; humans interpret a situation and find meaning as they interact, which affects their behavior (Blumer, 1969). Symbolic interactionism emphasizes action and process, meaning and emergence (Charmaz, 2000). "Life is patterned and it is the task of the researcher to uncover the patterns and explain their meanings" (Glaser, 2001, p. 180). For this study, the researcher interviewed participants in their natural setting, during the process of caregiving, allowing a conceptual understanding of the participants' main concern relating to hope and how they resolved it, using basic social processes, to emerge from the data.

1.4   Review of the Literature

In a search of the CINAHL and Medline databases (1987-2004), over 2000 sources were found that addressed the population of informal caregivers generally. A search of the same databases for references to hope produced over 1100 sources. A refined search was conducted for research articles examining hope and informal caregivers of palliative patients, only three research studies were found specific to both. Of these three, two sampled caregivers and one addressed family members of palliative patients generally, whether or not they were caregivers. The search was then broadened

to include hope research conducted with other populations of caregivers, and general research with informal palliative caregivers.

As recommended by Pinch (1995), the articles selected for the literature review were organized into tables. The tables identify the purpose, sample, design, instrument, results, implications, and give comments and a critique of each study. The articles were sorted into three categories; Table 1 contains articles specific to hope and other populations of caregivers, Table 2 contains articles specific to hope and palliative caregivers. Within each category, common themes were identified to integrate the results of the studies. The seven studies that were found to address hope and other populations of caregivers were reviewed, in order to add depth to the knowledge base of hope for caregivers.

1.4.1   Hope and Other Populations of Informal Caregivers and Family Members

Table 1 contains a summary and critique of the studies that examined hope and informal caregivers of other populations, including: caregivers of Alzheimer's patients (Irvin & Acton, 1997), of the mentally ill (Bland & Darlington, 2002), family members of persons living in a Canadian chronic care facility (Parse, 1999), spouses and relatives of critically ill adults (Gelling, 1999; Patel, 1996), spouses of patients undergoing heart surgery (Staples & Jeffrey, 1997), and significant others of people living with HIV/AIDS (Kylmä, Vehviläinen-Julkunen, & Lähdevirta, 2003). The research described in Table 1 was conducted in Canada, the USA, the UK, Finland, and Australia. One study applied quantitative methodology; five used qualitative methodology, and one a combination of both. Themes emerging from the research on hope and other populations of families and informal caregivers included: a) the relationship between hope, stress,

6

and uncertainty, b) the spiritual and religious aspects of hope, c) relationships as sources

of hope, and d) the active presence of hope in both caregiving and family relationships.

Table 1 Research on Hope and Other Populations of Caregivers/Family Members

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
Bland & Darlington (2002)	To explore the importance and meaning of hope for family caregivers of people with serious mental illness.	16 family members, Queensland and Tasmania, Australia.	Focused in-depth interviews, 18 total with 16 participants.	A team of researchers conducted the interviews. Participants asked to recall experiences, stories, or situations where hope was important, where they gained or lost hope.	Themes included temporal nature of hope, the connection between hope and loss, religious beliefs, spirituality, inner strength, and a positive attitude. Sources of hope were family and friends. Professionals gave hope and also caused a loss of hope. Progress of the illness affected hope as well as staying out of the hospital.	Hopefulness is central to a family's coping with mental illness. Issues of future orientation, positive expectation and realism. Families drew hopefulness from formal and informal supports, from within and without. Surrendering a hope of recovery, part of the grieving process. Protective role of hope, reactive to situation of the illness. Importance of recognizing the role of the family, giving support and hopefulness, and interventions to promote family well-being.	Researchers gave quotes to clearly describe themes in the data. Practical and useful information. However lack of scientific rigor, no stated methodology or framework, rather a thematic survey. Failed to give a conceptual description or interpretation of the data that would link the concepts or themes.
Gelling (1999)	To explore the relative's experience of hope when a family member is admitted to a neurosciences critical care unit following a severe traumatic head injury.	Relatives of 7 patients, UK.	Qualitative, not well described.	Interviews, Colaizzi strategy to analyze the data, NUD-IST 4 software.	Theory of "relatives' hope" in ICU emerged from the data. 7 themes were relationships, information, the past, the present, the future, loss of control, and emotions. Themes in combination help relatives	Importance of relationships, receiving information, uncertainty emerged (not validated with the literature). The research raises awareness of the importance of hope, encourages support to relatives, reassessment of hopes is always going on, encourage hope based on reality, involve relatives in decision-	Description of the research included, themes confirmed with the informants, quotes used to verify themes, credibility, transferability, dependability, and confirmability discussed. Themes not related to current literature of hope, more of a thematic

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
					formulate, maintain, and achieve meaningful and realistic hopes.	making.	survey than a conceptual or interpretive explanation of the data.
Irvin & Acton (1997)	To test how available self-care resources affect levels of stress and well-being, including hope as a mediating internal resource.	Convenience sample, 88 well female caregivers of Alzheimer's patients in early stages of the disease. 85/88 were white, well-educated.	Subjects from a larger study given questionnaires at support groups or through the mail, semi-structured questions asked through interviews for 29, and by mail, 59.	Completed measures of perceived stress, hope, and well-being, Memory and Behavior Problems Checklist, Miller Hope Scale, General Health Questionnaire.	Descriptive, correlation, and regression used. Hope was found to mediate the relationship between stress and well-being, tentative support for theoretically proposed linkages.	Caregivers had moderate levels of hope, hope levels correlate with well being, indicate it as a stress buffer, mediating between stress and well-being. Promotion of a positive orientation might be protective against caregiving stress.	Correlations between hope, stress, well-being ranged from 0.43 to 0.20, moderate positive relationship. Non-random samplings, non-representative of most caregivers, were help-seekers, well-educated, high levels of well being. Article did not show specific tables of statistics.
Kylmä, Vehviläinen-Julkunen, & Lähdevirta (2003).	To explore the dynamics of hope in significant others of people living with HIV/AIDS.	Publicity in newsletters and distribution of information sheets resulted in 6 significant others, Finland.	Grounded theory (Glaser and Strauss), qualitative, 11 interviews.	Interviews, unstructured, became more structured.	Dynamics of hope, alternations between 3 main elements, hope, despair, hopelessness and their reciprocal relationships. Wishing has a role. Basic process is searching for one's own way, changing from abstract to concrete.	Useful study to direct practice and future research. Significant others, not always active in caregiving.	Good data trail described, analysis included, using rigor of the methodology. Quotes used effectively. Data conceptualized into a model, offering a grounded theory, basic social process. Data also organized into a table, useful for practice.

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
Parse (1999)	To describe the lived experience of hope for family members of persons living in a Canadian chronic care facility.	10 family members of persons who live in a chronic care setting in Canada. Ethnically diverse sample of a variety of family members, spouses, children, parents.	Dialogical engagements, within the facility. The author did not give any details about the research design.	Not described, perhaps the researcher.	The structure of hope: the lived experience of hope arose as persistently anticipating possibilities amid adversity; intimate engagements emerge with expanding horizons. Stories of hope, the essences of each one described in the participant and researcher's languages.	Related to the author's previous works on human becoming, a theory of nursing, conceptualizing the experience from the family member's perspective has implications for nursing practice, philosophical but meaningful.	Author did not give any details of the scientific rigor to the study in this article. However quotes, stories, and interpretations were effective in describing hope at an interpretive level, data has been transformed and abstracted. Meaningful to nursing practice in developing relationships and being effective as a nurse.
Patel (1996)	To explore the hope-inspiring strategies that spouses of critically ill adults used while their family member was critically ill. Also what maintained or increased hope for this population.	20 spouses of patients hospitalized in an ICU for the first time, large hospital, USA.	Qualitative interviews used to explore and elucidate family member's point of view regarding hope.	Open-ended questions from a guide developed by Miller (1989), included in the report. Colaizzi analytic process used.	8 hope-inspiring themes categorized from the data: spiritual religious activities, significant others, devotion for the patient, positive relationships with caregivers, physical presence at the bedside, talking to others, and use of distraction mechanisms. Sources of hope	Active presence of hope, coping mechanism, 95% maintained hopeful state, even though 40% had poor prognosis. Hope is important to spiritual well being; search for meaning, all participants in this study had a religious affiliation, 90% Caucasian, all spouses.	Report detailed the process of the research, lending scientific rigor to the results. Models given of the conceptual description of the findings, study does not offer an interpretation of the findings. Lack of theoretical sampling, lack of a theoretical framework to guide the researcher, other than Lazarus and Folkman stress,

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
					were religion/faith, significant others, self, healthcare professionals, and devotion for the patient.		appraisal, and coping model. Practical and useful findings for nurses in this clinical area.
Staples & Jeffrey (1997)	To examine quality of life for cardiac patients versus their spouses prior to CABG surgery, secondarily to examine the relationships among uncertainty, hope, and quality of life for patients and their spouses before surgery.	Convenience sample of 21 couples from waiting lists at 2 hospitals in Ontario, Canada.	Descriptive, correlational	Farrens' and Powers' Quality of Life Index, Mischel's Uncertainty in Illness Scale, Herth Hope Index.	Greater uncertainty associated with lower quality of life and hope scores for patients and spouses. Spouses more uncertain and had higher QOL scores than the patients. More education correlated with higher hope levels. Both spouses and patients were generally very hopeful.	Need to incorporate the spouse into the plan of care. Presence of uncertainty affects care needs. Small, convenience sample, self-selection of participants.	Very good explanations of the tools used, demographic data, tables of statistics included, increasing reliability and validity. Several participants explained how they would not be having CABG surgery if they were not hopeful that the outcome would be positive.

Source: Author

11

1.4.1.1   The Relationship between Hope, Stress, and Uncertainty

Quantitative research with spouses of patients undergoing heart surgery suggested that greater uncertainty was associated with lower quality of life and lower hope scores (Staples & Jeffrey, 1997). Hope mediated the relationship between stress and well-being and was a stress buffer in caregivers of Alzheimer's patients (Irvin & Acton, 1997). The findings of these quantitative studies have limited applicability and generalizability as the samples were not representative of the larger population of caregivers. Irvin and Acton's sample was comprised of 88 self-selected female caregivers, of which 85 were white and well-educated. Staples and Jeffrey's convenience sample of 21 couples on a waiting list for heart surgery may or may not have been caregivers.

1.4.1.2   Spiritual and Religious Aspects of Hope

Religious beliefs, faith, spirituality, and inner strength were sources of hope and meaning for caregivers and family members (Bland & Darlington, 2002; Kylmä et al., 2003; Patel, 1996). Hope for family members of patients in long term care was defined as having a belief in God, maintaining positive expectations, praying, keeping going, rising above, expanding views, and being transformed (Parse, 1999). A lack of abstraction of the data, as described by Sandelowski and Barroso (2003) is evident in several of these studies. For example, Patel described the findings of the study but did not offer an interpretation. As well, a lack of scientific rigor limits the usefulness of these studies; both Parse and Bland and Darlington did not describe the methodological approach or the study design of their research.

1.4.1.3 Relationships as Sources of Hope

Family and friends were frequently cited as sources of hope (Bland & Darlington, 2002; Gelling, 1999; Parse, 1999; Patel, 1996). Parse described the experience of hope for family members of persons living in a Canadian chronic care term care facility. For these participants, relationships were essential to hope. Devotion to the patient and positive relationships with professional caregivers were sources of hope (Patel). Hope was conceptualized as a dynamic process of alternation between hope, hopelessness, and despair for significant others of HIV/AIDS patients (Kylmä et al., 2003). Hope was influenced by the presence of meaningful relationships that assisted significant others to rise out of despair into hope. The importance of relationships to hope was a common theme in all of the qualitative studies of hope and caregivers despite differences in the samples, the geographic location of the participants, and the methodology of the research.

1.4.1.4 The Active Presence of Hope

Hope had an active presence in critical care situations (Patel, 1996) and was crucial to the well-being and coping of spouses of critically ill adults. Bland and Darlington (2002) found hope to be a protective mechanism for family caregivers of the mentally ill. The progress of the family members' serious mental illness and staying out of the hospital affected the level of hope of the family caregiver. Parse (1999) conducted research with a multi-ethnic community of family members of persons in a chronic care facility. They described hope as persistent despite difficulties and always present.

The participants in each of the studies described in Table 1 were undergoing difficult family events, some life threatening (Gelling, 1999; Patel, 1996; Staples &

13

Jeffrey, 1997), others with a long, difficult trajectory of care (Bland & Darlington, 2002; Irvin & Acton, 1997; Parse, 1999; Kylmä et al., 2003). Hope remained a central theme. It was described as a part of the grieving process of mental illness (Bland & Darlington), a search for one's way through the stigma of AIDS/HIV (Kylmä et al), and a way to handle uncertainty (Gelling; Staples & Jeffery). A lack of abstraction of the data, as described by Sandelowski and Barroso (2003) characterized several of these studies (Bland & Darlington; Gelling; Patel).

Hope research with families and caregivers of different populations revealed the multidimensionality of the concept and its constant, dynamic presence in difficult life situations. The three research studies that specifically addressed hope with the population of palliative caregivers are described in Table 2.

1.4.2   Hope and Informal Caregivers of Palliative Patients

Hope was explored within the population of palliative caregivers using quantitative and mixed methodology studies. A quantitative study by Canadian researchers Chapman and Pepler (1998) examined the relationships between general coping style, hope, and anticipatory grief. The authors found a moderate relationship between these variables for family members of palliative patients. Hope correlated to confrontive coping, which is described as constructive problem solving. It also provided an incentive for constructive coping with loss. As only 33 of the sample of 61 family members were caregivers, the results may not provide an accurate representation of the experience of palliative caregivers. Quantitative research is difficult with this population; there are many variables to consider and a random sample may not be possible, therefore the results may not be generalizable. Chapman and Pepler

acknowledged several study limitations: self-selection of the sample, heterogeneity of the sample may have decreased the clarity of the results, and responses to questionnaires that may not give an accurate interpretation of the situation for family members of palliative patients.

The mixed methodology study by Herth (1993) utilized the Herth Hope Scale, a background data form, and a qualitative interview to explore the hope experience of a sample of palliative caregivers in the United States. This longitudinal perspective study concluded that hope was at lower levels at the beginning of the caregiving experience, then rose and remained stable. Based on the qualitative interviews, Herth defined hope as a dynamic inner power that enabled transcendence of the present and fostered a positive awareness of being. Herth reports that the qualitative data supports the findings of the Herth Hope Index. However, the overall hope scores on the Herth Hope Index, where hope rose and remained stable, are inconsistent with the qualitative results. The qualitative results described hope as dynamic, based on the inevitable difficult aspects of the palliative caregiving experience.

Herth (1993) and Borneman et al. (2002) did not mention the use of purposive or theoretical sampling techniques or a methodological approach guiding the qualitative interview content analysis. Borneman, et al. in their study of hope in 51 family caregivers, used Herth's concept of hope as a framework and found hope evolved from faith, connections with God and others, and strengthened over time to enhance coping. Hope was reduced by fatigue of the caregiver and poor symptom management of the palliative patient. Both Herth and Borneman et al. applied the Herth Hope Scale prior to the interview and used similar questions. The responses of the participants and the

results of the questionnaires may have been influenced by completing the Herth Hope Scale prior to the interview and sampling techniques selecting hopeful participants. Further research is needed to investigate the experience of hope during caregiving to add dimension to the concept and processes of hope for informal caregivers of palliative patients.

Table 2 Research on Hope and Informal Caregivers of Palliative Patients

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
Borneman, Stahl, Ferrell, & Smith (2002)	To describe hope and sources that promoted hope in family caregivers of cancer patients at home.	51 family caregivers in the sample, 10 were interviewed, USA.	Quantitative surveys with family members, every 5th asked to participate in a qualitative interview, content analysis applied.	Demographic data tool, Herth Hope Scale, interviews.	Caucasian caregivers more hopeful, older caregivers more hopeful. Interviews added meaning to the survey results; hope stemmed from faith, connections with God and others, object of hope changed, hope strengthened over time, realistic hopes evolved, finding joy each day, support systems, hope enhances coping. Barriers to hope were fatigue, symptoms not managed.	Confirms findings of Herth, hope is multidimensional and not easily defined. A connection to spirituality, faith, reiterates and redefines the concept of hope.	Actual caregiver comments organized by theme presented in a table, adding auditability. Use of HHS prior to interviews may have affected content of interviews. Self-selection, small sample not purposive or theoretical. Themes identified but not linked together into a theory or interpretation of the findings. Practical clinical information to enhance hope of caregivers, reciprocal nature of hope.

Chapman & Pepler (1998)	To examine the relationships among general coping style, hope, and anticipatory grief in family members of a patient with terminal cancer.	61 family members, not all caregivers. Canada.	Quantitative, exploratory, cross-sectional, correlational.	Jalowiec Coping Scale, Herth Hope Index, Non-Death Version of the Grief Experience Inventory, Background information sheet.	Family members experienced individual grief patterns.Emotive coping and hope accounted for significant variance in despair, somatization, and loss of control.	Complexity of concepts, 33/61 were caregivers, hope inversely correlated to emotive coping, and directly related to confrontive coping. Value of hope as a level, providing an incentive for constructive coping with loss.	61 in sample of 157 were contacted by the researchers, sample self-selection and bias. Paper confusing and difficult to apply at a practice level. An attempt to corroborate what qualitative research has shown.
Herth (1993)	Explore the meaning of hope, influence of background characteristics on hope, strategies to foster hope, in family caregivers of palliative patients.	25 family caregivers, USA.	Methodological triangulation, longitudinal.	Herth Hope Scale, interviews, background data form.	Hope defined as a dynamic inner power enabling transcendence of the present and fosters a positive awareness of being. Hope levels remained stable except for caregivers with poor health, fatigue, more than 2 concurrent losses, caring for an AIDS patient.	Interdependence of the care recipient and the care provider's level of hope noted. Hope-fostering categories included sustaining relationships, cognitive reframing, time refocusing, attainable expectations, spiritual beliefs, uplifting energy. Hope-hindering factors include isolation, concurrent losses, and poor symptom mgt.	Theoretical sampling not used. Lack of scientific rigor in the methodological framework and audit trail. Hope dependent on characteristics of the caregiver, care recipient and the environment, adds to the comprehensive understanding of hope by giving new interpretations of the concept of hope.

Source: Author

1.4.2.1 Comparing the Studies of Hope and Caregivers

There are similarities and differences in the findings of the hope studies represented in Table 1 and Table 2. Herth (1993) described the hope of caregivers of palliative patients as dynamic, powerful, and positive; whereas research with other populations such as the caregivers of the mentally ill (Bland & Darlington, 2002), revealed the temporal nature of hope, reactive to the situation of the illness. Staples and Jeffrey (1997), found hope decreased with increased uncertainty; Herth found hope increased over the trajectory of caring for a palliative patient. The importance of relationships to hope was similar across the studies in Table 1 and 2. The connection of hope with spirituality, faith, and religion was found in the studies in Table 2, as well as by Patel (1996) in spouses of critically ill and Bland and Darlington in family caregivers of the mentally ill. Maintaining hope was difficult for caregivers of AIDS patients as described by Herth and Kylmä et al. (2003). Kylmä et al. found significant others of HIV/AIDS affected people fought to rise up to hope from hopelessness, a finding not seen in other studies.

A synthesis of the results of the research on hope and informal caregivers of palliative patients and hope for other populations of caregivers revealed the importance and value of hope in the caregiving experience. The limitations of the available research highlight the need for the current study.

1.5 Limitations of the Reviewed Literature

Key limitations of many of the qualitative research studies, as described in the comments section of each table of articles include the lack of a conceptual analysis or interpretive explanation of the data, limiting the applicability of the results (Sandelowski

& Barroso, 2003). Scientifically rigorous qualitative research, with clearly stated methodology, theoretical sampling, and findings discussed in relation to previous literature is essential to ensure legitimacy, contribution to knowledge, and to inform policy and practice (Morse & Richards, 2002).

Many researchers have examined the perspectives of caregivers after the death of the patient (Bonnano et al., 2002; Davis et al., 1996; Duke, 1998; Enyert & Burman, 1999; Fakhoury, McCarthy, & Addington-Hall, 1997; King, Bell, & Thomas, 2004; Miettinin et al., 2001; Mok et al., 2003; Rhodes & Shaw, 1999; Rollison & Carlsson, 2002; Rose, Webb, & Waters, 1997; Sherwood et al., 2004; Strang & Koop, 2003; Yates & Stetz, 1999) limiting applicability of the findings to the experience of caregivers during actual caregiving. Hull (1990) in a longitudinal study of palliative caregiving, found that reflection after death was on the whole experience and caregivers were generally more satisfied with their role at that time.

Complex human relationships are difficult to quantify; the relationships of families and caregivers in a palliative care situation are very complex and the conditions of palliative patients are usually changing rapidly. Surveys and questionnaires may not reflect the actual view of the participants and information obtained tends to be superficial (LoBiondo-Wood & Haber, 2002). The quantitative research described in Appendix A examined family and caregiving issues in palliative care primarily using a correlational approach (Bonanno et al., 2002; Fakhoury et al., 1997), analysis of variance and causal modeling (Kristjanson et al., 1996; Kristjanson, Leis, Koop, Carriere, & Mueller, 1997), psychological inventory testing (Steele & Fitch, 1996; Stetz, 1987; Willert, Beckwith, Holm, & Beckwith, 1995) and survey-style questionnaires

20

(Hudson et al., 2002). Correlations show how variables are related to one anther, giving valuable information about relationships but are unable to predict cause and effect (Burns & Grove, 2001). The validity of the quantitative studies examined in the literature review may be questioned due to inappropriate sampling techniques including non-representative, biased samples of the study population.

The only Canadian research study to examine hope (Chapman & Pepler, 1998), sampled family members, not specifically caregivers, and resulted in a complex, quantitative analysis, difficult to apply to practice. The two other studies addressing hope and family caregivers were based in the USA; both used similar research frameworks and methodologies (Herth, 1993; Borneman et al., 2002). The process of hope within informal caregivers of palliative home care patients in the Canadian health care system is yet to be examined.

1.6 Key Conclusions

The literature review points to the need for ongoing research in hope and palliative informal caregivers. Ongoing, scientifically rigorous qualitative research is needed to conceptualize the experience of hope for Canadian caregivers, living with the patient, during the experience of caregiving. Based on the limitations of the reviewed literature, the author conducted a grounded theory exploration of the hope experience of informal caregivers, seeking an "insider's" perspective, during the time of caregiving.

1.7 Research Purpose and Specific Aims

The overall purpose of this study was to explore the experience of hope in informal caregivers of palliative home care patients receiving palliative care. The specific aims of the study were to: a) to describe the experience of hope in informal

caregivers of palliative home care patients, b) to generate a theoretical analysis of the hope experience of this population, and c) to develop statements of relationships between concepts regarding the basic social processes of the hope experience. Exploring the experience of hope in palliative caregivers adds to the understanding of the basic social processes involved in a complex situation. Based on the results of this study, recommendations to improve nursing practice may be developed, including hope interventions, supporting informal caregivers providing care to palliative patients at home. The proposed study adds to the understanding of the basic social processes of hope in the course of informal caregiving in a palliative care context.

2 CHAPTER TWO - METHODOLOGY

2.1 Research Design

As there is a limited amount of literature describing the experience of hope in informal caregivers of palliative home care patients, this study was conducted using a qualitative exploratory approach. This is an appropriate method when there is very little literature about a subject area (Brink & Wood, 2001). The design of the research applied Glaser's grounded theory methodology (Glaser, 1978, 1992, 2001). Grounded theory encourages the social organization of the people being studied to be revealed, to emerge, from their perspective (Glaser, 1992). The researcher chooses to become involved in the lives of the "experts"; the population being studied, going through the experience. The aim of grounded theory is to discover the underlying social forces that shape human behaviour, generating a theory which may serve as a conceptual framework on which to base subsequent quantitative studies (LoBiondo-Wood & Haber, 1998).

Glaser's grounded theory is based on a post-positivist philosophy, searching for the true meaning of the experience for the participants while acknowledging the influence of the values and viewpoint of the researcher. The generated grounded theory will exist in the data (Glaser, 1992). "A theoretical rendition of the realities of an action area is no less a reality provided; (1) it is grounded systematically in the data and (2) it is neither forced nor reified (concepts which relate to no data.)" (p. 14-15).

Persons have an active role in shaping the world they live in using symbolic interaction; the emphasis is on change, processes, and the variability of and complexity of life. Hope was identified in the literature review as a resource for informal caregivers. Grounded theory has been used to specifically address the dynamic, intra- and interpersonal nature of hope in other populations (Kylmä et al. 2003).

Grounded theory uses an emic perspective or "insider's" view of reality. In this study the emic perspective was sought by using open-ended, broad questions adapted to each situation. Concepts emerged from the data collected, which led to the development of substantive theory. The product of this research was a theoretical formulation about the experience of hope in informal caregivers of palliative home care patients.

2.2   Ethical Approval and Considerations

Prior to the commencement of the interviews, a proposal was submitted to the University of Saskatchewan's Behavioural Research Ethics Board. Ethical approval was obtained on January 20, 2004 (See Appendix B). A request was made to conduct the research in Prince Albert, Saskatchewan. A letter of official approval, dated February 2, 2004, was received to conduct the research in the Prince Albert Parkland Health Region (See Appendix C). Contact was made with the palliative care team in Prince Albert and a meeting was held on January 21, 2004, to discuss details of the study and the inclusion criteria. A handout with the details of the study was left with all members of the team. The Palliative Care Coordinator was the contact person for the researcher to recruit participants. The selection of the first participant agreeing to participate in the study was on February 16, 2004.

In order to obtain a larger theoretical sample, other agencies providing palliative care services were considered. In May, 2004, two agencies in Saskatoon agreed to identify potential participants and request permission from the caregivers to be interviewed. Four more participants were obtained from these agencies. The ethics committee at the University of Saskatchewan was kept up to date regarding this change in location of the research. No other changes were made in the research procedures.

Prior to the first interview with each participant, a written, informed consent was obtained; Appendix D contains a copy of the consent form. The participant and the researcher signed two copies of the consent form and a copy was left with the participant. Study participants were provided with an explanation of the process of maintaining confidentiality, as detailed in the consent form. All data was kept confidential; consent forms are being stored separately from the data. Only code numbers are used on the data and reporting was done in a group format. The data are locked in a file that only the supervisor and researcher will be able to access and will be kept for five years according to the University of Saskatchewan policy. The participants were informed of the research study purposes, any benefits or risks, and that they could withdraw from the study at any time without penalty. After consent was obtained, a demographic form (Appendix E) was completed before beginning the first interview in order to clearly describe the sample used for this study.

2.3   Sample

The sample inclusion criteria were: English speaking, men and women, 18 years of age or older, residing with and providing care to a terminally ill family member, and consenting to be a study participant. Participants were sought from a variety of

circumstances such as varying ethnic backgrounds, socioeconomic situations, religious affiliations, and various advanced diseases. As recommended by Charmaz (2000), a second interview was planned to be conducted with each caregiver, if possible, to validate the findings of the first interview and to give time for the participant to reflect on the discussion.

To obtain participants who knew the experience of hope during palliative caregiving, purposive and theoretical sampling was employed, as suggested by Glaser (2001). Sampling began where the participants were involved in giving palliative care and where participants have expert knowledge of what is being studied. After a core category was identified, the researcher began theoretical sampling, in order to obtain theoretical completeness, going to similar units in other contexts, choosing new participants on the basis of what they could contribute, comparing the data, asking new questions, and looking at the literature. Theoretical sampling proceeded at the same time as coding, analyzing, memoing, delimiting, and saturating. Theoretical sampling allows the researcher to develop the emerging categories, to identify their context, conditions, and consequences (Charmaz, 2000).

There is no formula to determine the sample size in qualitative research (Morse & Richards, 2002). The number of participants was determined by the quality of the participants' experiences, their ability to reflect on and report their experiences, and the requirement for further theoretical sampling. Sample size was determined by saturation. Data collection was considered complete once saturation was reached. Saturation took place when the categories seemed complete and all new data were fitting into the categories that had emerged from previous data.

2.4   Setting

Data collection began in Prince Albert, the third largest city in Saskatchewan, located near the geographical center of the province. Prince Albert does not have a cancer center; patients and caregivers must travel 141 kilometers to Saskatoon for cancer treatments and follow up from an oncologist. However, Prince Albert has a well-developed palliative care team, composed of social workers, nurses, physicians, dieticians, spiritual care providers, and pharmacists, meeting weekly for integration and coordination of services. Four participants were obtained in Saskatoon, the largest city in Saskatchewan. Saskatoon has a cancer center, which alleviates the stress of traveling to appointments. The team responsible for palliative care in the community meets quarterly and is comprised of nurses, social workers, dieticians, spiritual care providers, physicians, occupational therapists, and physiotherapists.

2.5   Obtaining Study Participants

The palliative care coordinator referred suitable caregivers, who had consented to be a part of a research project and met the eligibility criteria. One potential caregiver was unable to participate as planned, as the condition of the palliative patient was worsening quickly, ultimately dying before the interview could be commenced. The palliative care coordinator in Prince Albert reported that many other participants were approached and declined to be interviewed due to their own level of stress and discomfort. The difficulties doing research with palliative caregivers, including accessing and interviewing this population, became apparent. During one interview, the patient was in the emergency department, following a seizure that had occurred that afternoon. The interviewee still wished to participate in the interview, even though the

27

situation was very uncertain within the household. A review of the literature, described in Chapter One, revealed the experience of palliative caregiving is one of stress and demand on time, and physical and emotional energy. The trajectory of palliative care is unpredictable; the early phases may involve accepting the prognosis. The coordinator in Prince Albert did not feel comfortable asking caregivers to participate too soon after referral to the program. Patients were also being moved into the hospital, either for symptom management, respite, or to be placed in long-term care. This too, limited the number of participants. In one situation the caregiver declined a second interview as the patient was being transferred to hospital and died a few days later.

In June, 2004, the researcher contacted the Past-President of the Hope Cancer Help Center in Saskatoon, who contacted and received consent to participate from an additional three participants. A nursing manager from Nightingale Nurses' Group in Saskatoon obtained informal consent from an additional one participant. Ultimately, ten caregivers were interviewed by the researcher; eight of these were interviewed twice. One participant declined to be interviewed a second time as the patient was being admitted to the hospital, another caregiver was not interviewed a second time due to caregiving issues. Saturation was reached with 16 interviews. Two interviews with participants were completed for confirmation of the findings. A total of 18 interviews were conducted.

2.6   Data Collection

Data collection involved obtaining consent (See Appendix D), the completion of a demographic form (Appendix E), open-ended interviews, and the writing of field notes and memos in a journal. After receiving the name of each participant, a phone call was

made by the researcher as soon as possible, to set up a suitable time for an interview. Various arrangements were made to accommodate work schedules and rest times of the patient. The questions to be discussed were introduced to the participant during the initial phone call, in order to allow caregivers to reflect prior to the interview and enhance the data collection. All interviews with the exception of one participant were conducted in the home, by the researcher, in a private area where comfort and openness of the participants was encouraged. Open-ended qualitative interviews were used to focus on hope with informal caregivers, studying them in their natural setting during the experience of caregiving.

2.6.1 Demographic Form

Following completion of the consent form, the researcher completed a demographic form. Information recorded included age, gender, relationship to patient, occupation (current or past), ethnicity, income, religious affiliation, medical conditions, and education level. Patient information such as age, gender, diagnosis, and date of admission to the palliative care program, length of caregiving, and date of death of the patient was collected. Appendix E contains the demographic form.

2.6.2 Open-ended Interviews

After consent was obtained and the demographic form completed, a face-to-face interview was conducted with the informal caregiver in a convenient location. To prevent fatigue, interviews were kept to a maximum time of 60 minutes. In three situations, the male spouse caregiver preferred the patient to be present for the interview. This was accommodated without difficulty, as questions were directed to the participant and the patient mostly listened and contributed occasionally. The interviews

conducted in this way were very insightful into the dynamics of the family and possibly of benefit to the couple, as open communication about difficult yet meaningful topics was pursued. One caregiving couple was interviewed together.

Broad, unstructured questions were followed by more specific questions, adapted to each individual situation. For example, "What gives you hope?" "Does your hope change?" and "Are there times when you haven't felt hopeful?" Open-ended questions allowed the details of the research question to be defined by the participants as they described the research problem in their own way. See Appendix F for the interview guide. As recommended by Glaser (2001) the interview questions were designed to invite conversation about the topic; the exact wording was amended based on the nature of the interviews and the responses of the participants.

As data analysis progressed the questions were changed to become more focused with concurrent analysis of the data. After the fourth participant was interviewed, the interview guide changed to reflect a focus on the main concern and basic social process, see Appendix G. At the close of each interview, a time of validation and debriefing was conducted with the participant. Field notes were recorded of the setting, environment, nonverbal communication, and interactions of the participants with others and their environment. Following each interview, the researcher recorded immediate thoughts and feelings about the data collected during the interview.

In qualitative research, the researcher is the primary instrument for data collection (Morse & Field, 1995). The researcher must have credibility and skill to gain, build, and maintain trust. The researcher was previously a palliative home care nurse in Saskatoon, not currently providing care to any of the participants. This allowed the

participants to feel assured their care would not be affected, and that the researcher understood and was comfortable with their situation, establishing credibility and trust.

2.6.3 Journaling

The researcher used a journaling technique, in the form of memos, throughout the research process to capture ideas, insights, thoughts, and feelings about the relationships between the concepts in the emerging theory. Initial observations and patterns were reflected on, discussed with the researcher's supervisor, and compared to established theories from the literature, attempting to ensure that any personal biases were not affecting the results. Clarification was sought from further interviews with participants; questions were changed to reflect the ongoing findings from the data.

Journaling also allowed and encouraged the researcher to write down thoughts, ideas, beliefs, and values in order to check if they were affecting the data being collected. By examining personal beliefs and potential judgments that may occur during data collection and analysis the researcher is more likely to keep an open mind and differentiate between the participants and the researcher's ideas, comments, and activities (Speziale & Carpenter, 2003).

2.6.3.1 Researcher Role

The researcher is a palliative home care nurse with more than 15 years of experience in this area. This provided some possible biases and preconceived ideas in the data gathering, as well as a depth of understanding about the experience of caregiving. The researcher was able to establish rapport easily and quickly, as the caregivers felt comfortable with a registered nurse who has experienced many similar situations. At times the researcher was tempted to become involved in other aspects of

nursing care and had to remember to maintain appropriate boundaries. Focusing the conversation on the experience of hope required effort, but was a very rewarding, intense, and exciting process.

2.7 Data Analysis

"Grounded theory requires that coding and analyzing go with the collecting immediately, leading to categories, memoing and delimiting, hence where to sample next" (Glaser, 2001, p. 169). Grounded theory methodology was applied to the data analysis, simultaneous data collection and analysis was ongoing throughout the time of field research (Charmaz, 2000). All interviews were audio taped and transcribed verbatim for analysis. Field notes were transcribed and used to interpret the data. Data were analyzed after each interview during data collection and before commencing the next interview.

Data was entered into Non-numerical Unstructured Data Indexing, Searching, and Theorizing (NUD*IST- 6) Software for analysis. The data was examined line-by-line, processes identified and coded, and underlying patterns conceptualized. Coding at three levels occurred: open coding, constant-comparative coding, and theoretical coding. Open coding keeps the researcher in the data, not allowing personal beliefs and theories to be imposed on the data, staying attuned to the participant's view of reality (Charmaz, 2000). Coding kept the researcher thinking about the meanings in the data, asking questions, and looking for the gaps and ideas to focus on in subsequent interviews. Open coding was completed when the basic social process of hope in informal palliative caregivers at home was identified. Constant-comparative coding was then used to compare incident with category and category with category or concept. Charmaz

describes constant comparative coding as comparing different participant's viewpoints and experiences, comparing data from the same individual with themselves at different points in time, comparing incident with incident, and comparing data with category, and comparing a category with another category. See Appendix H for a sample of the coding process applied to the data.

Theoretical coding involved examining relationships among categories or concepts. Relevant literature was selected and integrated throughout, to help the researcher fill in the missing pieces of the emerging theory. Selective sampling of the literature occurred throughout the analysis to help the researcher fill in the missing pieces of the emerging theory.

Memoing was used, following a memoing process as described by Glaser (1978). Memoing encourages the development of ideas throughout data collection and analysis, enhancing theoretical sensitivity. As recommended by Charmaz (2000), memoing is used as the intermediate step between coding and the first draft of the analysis. Raw data and the researchers developing ideas were brought into and discussed in the memos, reflected on, and analyzed as concepts emerged.

2.8   Scientific Rigor

Credibility, auditability, fittingness, and conformability are the specific criteria used to judge the scientific rigor of qualitative research (LoBiondo-Wood & Haber, 2002). To establish creditability, or the truth of the findings, audiotapes were transcribed verbatim and the participants' language used to code, categorize, and write theory. Credibility was established by confirming the results of the interviews with participants at a second interview. Auditability was achieved by keeping raw data, field notes, and

memos, providing an audit trail of the various steps from the raw data, to analysis and interpretation. Grounding theoretical observations in the data and cross-coding and categorizing data ensured fittingness. The researcher and her supervisor independently coded selected transcripts throughout the study, and compared the results. Confirmability is ensured when the criteria of credibility, auditability, and fittingness are met (Duggleby, 2000; LoBiondo-Wood & Haber).

The criteria for evaluating grounded theory analyses are fit, relevance, workability, and easy modifiability (Glaser, 2001). Grounded theory works when it provides a useful conceptual rendering of the data, analytically explains the actual concerns of the participants and the basic social processes used to resolve those concerns (Charmaz, 2000). Charmaz explains that a grounded theory is durable and flexible; it can account for variation, and can be modified as conditions change and further data is gathered. The researcher has examined the processes of hope in caregivers of palliative patients, acknowledging that the social world is always in process, change is ongoing, and the data obtained is a moment in time, a brief glimpse into the lives of caregivers.

3   CHAPTER 3 FINDINGS

3.1   The Sample

Saturation was reached with 10 participants. A total of 18 interviews were conducted. Demographic characteristics of the participants are described in Table 3. The age of the participants ranged from 29 years to 74 years of age with a mean age of 55 years. Length of caregiving ranged from six months to six years. Fifty percent of the caregivers interviewed were female and 50% male. The majority of caregivers were Caucasian and one First Nations caregiver participated. Fifty percent of the participants stated they had no religious preference, 30% stated they were Protestant, 20% Catholic. Most of the caregivers were spouses of the patient, the rest were sons and daughter-in-laws of the patient. Ninety percent of the patients had a cancer diagnosis. Most of the participants were in the middle to high income ranges.

Table 3 Demographic Characteristics of Participants n=10

Characteristics	Number
Gender:	
Male	5
Female	5
Ethnicity:	
Caucasian	9
First Nations	1
Religious Preference:	
None:	5
Protestant:	3
Catholic:	2
Description of Caregiver:	
Spouse:	6
Daughter-in-law:	2
Son:	2
Years of Education Completed:	
Less than 13 years:	5
14-16 years:	3
More than 17 years:	2
*Income:	
Low:	1
Low-Middle:	2
Middle:	3
Mid-High:	1
High:	3
Primary Diagnosis of Patient:	
Cancer of the Breast:	4
Lymphoma:	2
Cancer of the Pancreas	2
Cancer of the Lung	1
Other	1

Source: Author

*Categories of income determined as follows:
<$20,000 Low income
$20,000-29,000 Low-Middle
$30,000-39,000 Middle
>$40,000 Middle-High
>$60,000 High

3.2   Hope

Hope was defined by the participants as inner strength that gave them the courage and ability to go through a difficult situation. It was dynamic and a choice. One participant said: "It's just inside you that you have that feeling…you're going to keep on trying as long as you can." Another said: "Hope gives you the courage and your courage gives you hope." Hope gave caregivers the strength and courage to go through difficult situations.

There were many difficult situations for the caregivers in this study. Caregivers described "hard-towing, sometimes" and "living with stress". Hope was a choice, at times things became so difficult the caregivers felt like walking away from the situation: "There's moments I say, I want out." One participant said: "I think you have to choose what works for you." The dynamic nature of their hope experience was expressed as frequent ups and downs in their hope, but caregivers were able to choose strategies that helped them to hang on to hope.

The focus of the caregiver's hope was for the patient, for themselves, and for their families. Caregivers hoped for minimal pain and suffering for the patient, or for a miracle, not giving up their hope for a cure, or a remission: "Our main goal is making her as comfortable as she can [be]…we're hoping she gets through this with the least amount of pain and the most dignity she can." "I hope she stays healthy," and "She's defied so many odds." For themselves, caregivers hoped they would be able to handle whatever an uncertain future would bring and hoped to do a "good job" of caregiving without giving up: "I try to do the best I can…you just don't throw your hands up in the air and give up."

Without hope, caregivers imagined life would be "bleak" and "a waste of good time:" "You would have nothing to get up in the morning for." Participants suggested they would become "grumpy and depressed" or "bitter and angry," acknowledging that "some people turn to suicide" if they were to lose hope. One participant said, "If you're going to be bitter and angry about it, you'd be wasting your time down there." Another participant said: "Without hope it would be really hard to cope with looking after her; I think that you'd just completely give up." One caregiver described his personal struggle with alcohol throughout his life, which resulted in his need for anti-depressants to treat a "nervous breakdown". When asked what he would do if he didn't have hope he said: "I don't know, take a stronger pill I guess." Participants described how easy it would be to give up, lose hope, and get depressed, even suicidal if they did not have hope: "If you got down on it, you'd get depressed fast."

The process of open coding resulted in the identification of a basic social problem and a basic social process. From the analysis of the transcribed interview data, the basic social problem for caregivers of palliative patients was "eroding hope".

3.3 Eroding Hope

Participants described the problem with hope as "it keeps getting eroded" or "it doesn't go away, it just gets chipped away at." The fluctuations and waves of hope were described by one participant as: "Hope is never steady at all; it's always kind of in between…it changes every day, even by the hour sometimes, it's never steady at all, up and down and around and curves." A caregiver vividly described the experience as: "I call it a wave, up and down; up and down, how long can you stay in the valley? You

want to stay there and be hopeless, but you can flow back up again, and say okay, building, there's building." One participant said: "Some days there wasn't much hope."

For many caregivers, there were frequent unexpected events in the caregiving experience that led to an erosion of hope. A discouraged male spouse caregiver explained the process of eroding hope as "with her, its always one step forward and two steps back, you're always waiting for the next shoe to drop, and it always does." A female caregiver described stressful, busy days as times when your hope gets eroded: "Most often when you're busy and things keep happening, you have limited brain power and you just kind of fall off the edge eventually."

Experiences with the health care system sometimes resulted in an erosion of hope, mostly from difficulty communicating with professionals and not being treated like a human being. Qualitatively, the findings were not different across the two settings of the study. A participant described her experience at the cancer clinic: "Even though we ask…they use these big words and so you tell them and they use another big word, so you get frustrated not understanding all the medical terms." At times, caregivers felt like numbers, or feeder stock for the system, rather than human beings: "being treated like a number that has to be explained on a chart somewhere." An angry caregiver expressed his dissatisfaction with his wife's hospital experience: "Basically, I'm angry at the system…it's an impersonal system…the patients are kind of feeder stock to keep the system going."

Another family described their fight to have the doctor tell their mother about her terminal condition: "Eventually we had to tell her ourselves at a family meeting, I

mean, she was lucid, she needed to know her own condition and the doctor would not tell her, that was very frustrating."

"Bad days" chipped away at hope; meaning symptoms had become out of control. One participant described her frustration with seeing the "hurting and suffering and not being able to do anything to make it better." "Seeing the pain" and "knowing what's ahead" caused the level of hope to flow downward, but all participants agreed there was always some hope remaining. One participant said: "You don't survive without hope".

Negative messages eroded hope: one participant remarked "He's been told so many times (referring to his diagnosis), it's written on his forehead!" Another participant resigned herself to the experience: "It's what going to the cancer clinic is like…there's nothing I can do about it." A spouse described a situation in the hospital: "You're not giving us much hope here…there wasn't much hope to give; another family would have lost hope." "Of course, it doesn't always work smooth, sometimes you get slapped back again and you realize you've got to start over." Caregivers faced the problem of eroding hope by using the basic social process of "hanging on to hope."

3.4   Hanging on to Hope

Participants resolved their main concern, the problem of eroding hope, by using the basic social process of "hanging on to hope". The participants used the exact words: "hanging on to hope" to describe a conscious, active process that required energy, focus, and at times, a fight. Hanging on to hope meant, according to one participant: "…never giving up on hope, never, never, never, never, never, never, no." Another participant described the experience as "hanging on to hope, sometimes by a frayed thread". Hope

was seen as necessary to survive the experience. One participant said: "We just hung on", another said: "We all managed to hang on to hope, what you can, you know."

Some caregivers reflected that occasionally they forgot their new ways of living every day that facilitated them to hang on to hope. They had to remind themselves to "get back on track," especially during good times when they may not be thinking about how to hang on to hope. The times when their hope was being eroded made them more conscious of choosing the active process of hanging on to hope: "We try to live today as well as we can…but sometimes we lose sight of that [when things are going well] and need to get back on track."

3.4.1   The Sub-Processes of "Hanging on to Hope"

The sub-processes of "hanging on to hope" were identified by the process of comparing incident with incident, category with category, and category with the concepts that were emerging. The sub-processes include the concepts of "doing what you have to do", "living in the moment", "staying positive" and "writing your own story." The support of family, friends, health care professionals, and "connecting with something bigger and stronger than you," were sub-processes that together, directly affected movement within the other four sub-processes. The processes were not linear, often occurring simultaneously, circularly, and interchangeably, possibly resembling an upward spiral. Figure 1 is a diagram of the concepts, the basic social process of "hanging on to hope" and its sub-processes. The upward spiral denotes a trend upwards within the sub-processes. "Doing what you have to do" was a starting point that allowed caregivers to progress to "living in the moment", "staying positive", and "writing your own story". Not all caregivers were able to attain all the levels, depending on the

41

experiences they were going through at the time and the processes they were using to face them. The fluctuations of hope were evident as movement was constantly occurring within the sub-processes.

Eroding Hope

- Bad days
- Negative messages
- Experiences with the health care system

Palliative
Diagnosis

Hanging on to Hope

- Supporting relationships
- Connecting with something bigger and stronger

- Writing your own story
- Staying positive
- Living in the moment
- Doing what you have to do
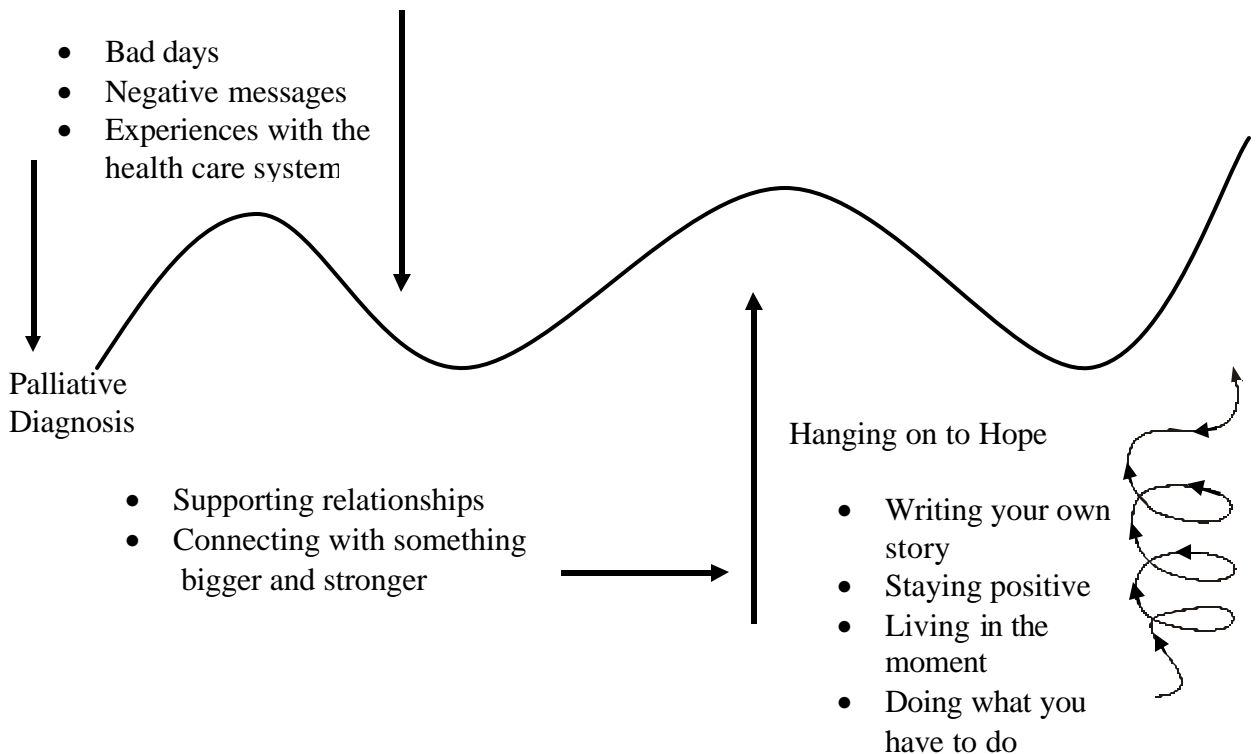
Figure 1 - The Process of Hanging on to Hope in Informal Caregivers of Palliative Home Care Patients

3.4.2 Doing What You Have to Do

All of the participants described the process of "doing what you have to do" as a way of hanging on to hope. A participant said: "We just do what we have to do, and get through it." "Doing what you have to do" meant being willing to just "be there", willing

to be a caregiver for a family member with a life-threatening condition. Several participants reflected on the need to "be there" through difficult circumstances in order to learn ways of hanging on to hope. One participant described it as: "You don't truly know what it's like unless you've been there."

The ways of "doing what you have to do" were: "accepting the situation", "not giving up", and "recharging". For example, one participant described her experience as learning to "deal with things in a faster, less destructive way. You still go through it, you have to deal with it, but you don't spend as much time spinning your wheels, you see how to go forward better."

3.4.2.1   Accepting

Accepting whatever was happening allowed the caregiver to begin doing what they had to do and deciding to make the best of it. One participant said: "You have to accept what happens and then work your way through it." Another participant described the process of accepting and going through it as:

> It's something we have to accept, and that's pretty well the only way I can deal with it. The easiest way for me to deal with it, it's all part of life - we accept what we are given and deal with it the best we can. You have to deal with it and just go on.

A caregiver described her process of acceptance as: "Not necessarily liking it, but again, not being in denial, but owning what is and going back to the positive of saying 'Okay, that's the way it is, with the time we have, we're going to do well with it."

3.4.2.2   Not Giving Up

Courage, persistence, determination, and at times, aggression, characterized the reaction of the participants to eroding hope as they decided to not give up. A participant described his determination to not give up as: "You just never quit, keep putting one foot in front of the other, one way or another, things will work out." One participant said: "You don't give up...your assumption is that you will get through it, it never occurs to you, really, that you're not going to make it through in some way."

One caregiver approached his situation with a fight: "Most people would give up on this thing… [but] you don't give up…you keep slugging, you do everything possible." Another participant said: "We're in it for the long haul, we're not going to give up, or quit, [we are] like a team." Caregivers "doing what they have to do", needed periodic recharging in order to get through the experience, accept what they had to do, and not give up.

3.4.2.3   Recharging

Participants described their need for a "recharging" process, as a way to "do what they have to do" and hang on to hope. One participant said: "I always kind of recharge my batteries at night. I pray and read something…I don't want it to show on the outside." Recharging allowed caregivers to go through each day with a positive, hopeful energy. "There's times when I've had enough and I go for a walk, or whatever, I need a break." A caregiver, when recognizing his "batteries were low" would have a little sleep, and get back on track. Another stated "It takes that sitting down…charging my batteries…helping me with the idea that I could muster up the hope I needed."

Several participants identified the need to recharge as a deliberate action to avoid "burning out," and hang on to hope. For example one participant said: "As a caregiver we tend to put our needs last… we over-care-take, and burn out." Ways of recharging included getting outside, going for a walk, going to work, going away for the weekend with someone else providing respite, or just taking quiet moments of prayer, reading, or resting.

3.4.3 Living in the Moment

"Living in the moment" was a sub-process used by caregivers to hang on to hope by re-focusing their thoughts and actions on "the very present." An uncertain future was the stimulus to live in the moment: "You change your focus from far ahead to right now." One participant said: "You never know what is going to happen; you just go day by day." Another participant described her way of living in the moment as: "Everything is easy because today is what we're trying to make as good as it can be." Living in the moment was described as: "It's doing rather than planning; it's about not writing the future before it happens. You never give up the idea that there's a future...you just do the next thing…it will eventually lead to something." Participants described ways of living in the moment as, "knowing what to do", "keeping things normal" and "not looking too far ahead".

3.4.3.1 Knowing What to Do

Knowing what the patient needed and being able to meet those needs while "making every day a little special" was described by the participants as a positive aspect of caregiving: "If you know you're doing a good job…it definitely helps with hope." A participant identified the need to take "small steps" narrowing the focus of their energies

to keeping the patient comfortable and happy, enjoying when they could "make her smile."

Participants felt more hopeful when they knew how to handle the care and manage the symptoms of the patient as they arose. Knowing when and whom to call and having a "back-up plan" in place to be able to care give in their home helped caregivers cope on a day to day basis. Caregivers "learned on the job", as one participant said: "If it hasn't been a good day, maybe tomorrow will be better, you avoid the pitfalls that made it a bad day." Having information gave them confidence and skill to make decisions about their futures that they were comfortable with: "[The cancer] can be very aggressive, and then all of a sudden, it can slow up for awhile and relieve things. So you know, it does give you hope." Another participant said: "…in order to deal with what I had to deal with, I learned what I needed to know to do that."

3.4.3.2   Keeping Things Normal

For all of the participants, "hanging onto hope" was facilitated by the patient being at home, in a surrounding that fosters "keeping things normal". When the patient was at home: "You don't class him as sick anymore, so your hope builds". For one caregiver, the focus of hope became: "making her as comfortable as she can be, and as normal as you can until the end, that's what we are hoping for." One participant reflected on the difference between hospital and home: "You appreciate when things are normal; when you are in the hospital, or away from your loved ones, how much harder it is to cope…and I hope it can stay like that." Caregivers hoped to keep a normal life as long as possible: "but just the same, it makes things more normal now."

3.4.3.3 Not Looking Too Far Ahead

Looking too far ahead was described as "dangerous" by one participant. Another said "you don't look up, you don't hang a picture up of where you're going to be, you just have to deal with what you have to deal with that day." A participant said: "It's about not writing the future before it happens." Living day to day was a strategy described by all of the participants, looking too far ahead made caregiving seem more difficult and too overwhelming. The future was uncertain and unpredictable. Living in the moment was an essential process for hanging on to hope, occurring simultaneously and interchangeably with "doing what they have to do," and the other sub-processes.

3.4.4 Staying Positive

Staying positive allowed caregivers to continue "hanging on to hope". One participant said: "You look for something positive, and you carry on with that. Anything that isn't negative, any positive contribution is what is helping." Other participants said: "I'd rather think positive…", "…we're assuming a positive outcome," and "…you have to have a positive attitude." Caregivers realized that hope allowed them to turn their difficulties into positives: "without hope, you can't do all the good stuff," "We're not grieving 'till we have to, not wasting time, the good time" and "We want to have a positive attitude in what we are doing." The ways of staying positive were looking for the good things, putting away the negatives, and appreciating the situation.

3.4.4.1 Looking for the Good Things

Participants looked for the good things about the difficult situation they found themselves in: "I look for the positives to carry on with." They learned to identify the "good things they could go on." A reflective caregiver described her strategy for staying

positive: "When we go to bed at night [we say] it's been a good day, everything worked out, if it hasn't you just say, maybe tomorrow will be better." Hopeful participants saw life as good, but temporary, and the need to put away the negatives and appreciate it.

3.4.4.2 Putting Away the Negatives

In order to stay positive, hopeful participants learned to put the negatives away, to the back of their minds. One caregiver's approach was: "I don't think 'Why me?' or 'Why us?'-there are no answers, so I don't waste my time," and others said: "I don't want to wallow in it," "I don't get depressed about it," and: "I try not to get negative about it, I try to stay positive." One caregiver's approach was: "We come home [from the cancer clinic], and we try to build this back up again, we try to forget the doctor's words." A participant gave the reason to avoid negatives as: "We make the most of good time…we're not going to grieve until we have to". Another participant said: "We're assuming things are going to work out, there's no hope otherwise."

Several participants were careful to choose what they read, who they talked to, and who visited, in an effort to put away negatives and stay positive. Participants tried to stay away from support that was not helpful: "The permutations are endless as what kind of support you can get, but there's a lot of it that's not, not good. There's a lot that's not useful…it's not ill-meaning, it's just not helpful under the circumstances."

3.4.4.3 Appreciating the Situation

As the focus of each day became living in the moment and staying positive, caregivers learned to appreciate life more, reflecting on both the present situation and the past. Everyday tasks like reading the newspaper became a "privilege to do them. You don't take anything for granted." "We really are really lucky when you think of

it…everything worked out; we've had such a happy life together." One participant said: "You have to think you got your share of the good times." Another caregiver said: "We've had a good life, we've said that lots." Caregivers focused their energy on choosing to "appreciate life." One particularly reflective participant summed it up: "I think that with anything that's hope, there's a lot of appreciation for what went on before…like you don't get hope unless things have worked out for you."

Caregivers learned to appreciate their own situations by comparing them with others, and discovered their strengths and abilities to handle their own problems. Many caregivers identified with and were thinking of others in similar or more difficult situations: "I really feel for people like that. It must be really hard." "I think of them in their time of trouble." Participants said: "Things could always be worse," and "you can always find people who have a lot more problems than you!" As one participant said:

> …there's a lot of people that don't have what we had, or didn't have the time together, or when you think of people that have children that have problems…I think that must be such a disappointment…cancer is a terrible thing, but there are so many other things, like losing a person before they are gone.

3.4.5 Writing Your Own Story

"Writing your own story" was identified by caregivers as a process involving staying in control over difficult circumstances and making decisions about what their own future and the future of the patient would look like: "We're doing everything possible…because he's not going with that story, the way we want to do it...I'm hoping we can." Caregivers demonstrated determination and commitment to the patient: "We're in it for the long haul, we're not going to give up, or quit, or whatever, until we really need to, you know." It was a shared story; the caregivers' story was based on what was happening to the patient. Caregivers worked together with the patient to find a way to

handle the prognosis they had been given: "He's writing his own story; with a different ending than the one they have for him."

3.4.5.1   Staying in Control

Caregivers needed to feel that they were in control of their own situations in order to remain hopeful. A caregiver described staying in control as: "Its part of being hopeful, I think that you feel you're not prey to whatever comes along...if you feel that you have some modicum of control over how to deal with it and how to accept it." Caregivers wanted to feel in control: "If I could get that feeling back that we're in control again." For some caregivers that meant fighting the system: '[You] just don't take it, is it's not going your way, don't believe them, just keep slugging, if you don't, nothing will improve." Another caregiver said "We talk about them (the medical system), and then say, to hell with them, let's go on." Staying in control also involved making decisions about your own future.

3.4.5.2   Making Decisions about Your Future

Caregivers wanted to decide their own situations whenever possible: "We'll decide what our situation is. Thankyou." and "We all know that everyone's situation is different and no one can predict the future." They appreciated when health care professionals allowed families to explore options and ideas, choosing to "work with you", rather than saying "there's nothing we can do for you, go and make your wills."

Caregivers dealt with the cancer clinic's requests to offer treatment. One caregiver stated: "I said, Mom, this is your [option]...finally I phoned them (the cancer clinic) and I said, 'we talked it over and mom doesn't want to lose her hair and be vomiting worse than she is all the time'…I said she doesn't want that." Once palliative

care became involved, the caregivers were thankful for the options offered to them: "once we got on track with them, then you know what you're doing." One participant said: "Just because you're on palliative care doesn't mean it's over; it kind of perked me up, yes, there's hope for tomorrow."

All of the sub-processes of hanging on to hope were intimately connected to the two sub-processes of supporting relationships and connecting with something bigger and stronger than you.

3.4.6   Supporting and Connecting

The basic social process of hanging on to hope, depended on "supporting relationships" with family, friends, health care professionals, and "connecting with something bigger and stronger than you." (Refer to Figure 1). All participants identified having support as extremely important. One participant said: "Lots of support from everywhere, it helps a lot, it actually is huge, other wise I'd have gone crazy."

3.4.6.1   Supporting relationships

Supporting relationships were seen as crucial to hanging on to hope. Support came from many different sources such as family, friends, and health care providers. Caregivers discussed the importance of the positive support they received from health care professionals in both settings of the study.

"Having family in it together with you" was a source of security through difficult times and a hope for the future. As the family "pulled" together, the caregiver was able to stay positive, not give up, and remain hopeful. Caregivers felt secure in having family in the situation together with them, and were able to hang on in very difficult

circumstances. One participant described the feeling of oneness and security she had about her family support:

> We're all in the same verse, they're all very much in tune with it, they're in the same mind with me...if it goes this way, well then I have my family - you're ready to make the tradeoff if you have to. I always think you're safe, as long as you have family.

Caregivers demonstrated commitment to caring for each other within the family unit: "with everything that we've had to go through, he's always looked out for me, or I've looked out for him, so I wouldn't want to let down my responsibility."

Caregiving couples, children of the patient, depended on each other for support; "Well, we have each other. If (name of participant) was here by himself, he probably would have gone crazy." Couples would take on different roles and help each other get through. One participant said: "Oh yes, we talk, we have good communication, we help each other that way."

Connecting with family, friends, and supportive professionals was facilitated by "talking about it". One participant had a discussion with her husband after the first interview with the researcher, and stated: "When we talked about it, I felt better; we were in the same mind." One participant said: "Even a little chat, it all helps." Talking allowed caregivers to discover each other's feelings, frustrations, and hopes for the future, and build "closer" relationships that gave greater support.

One caregiver described the importance of support from his family and friends: "Having friends around helps me, there are a lot of people that made the difference…they were critical, that kind of support…you know that they're sympathetic. There's not much they can do, but they're there and they're pulling for you, and that helps a lot."

Support from caring, positive professionals gave hope for many participants. "Talking to the palliative team, once we got on track with them, then you know what you're doing, before you were blind." Some participants were relieved when the patient had someone outside the family to talk to, about issues they were uncomfortable bringing up. One participant said: "Home Care is a terrific delivery of hope for me…encouraging things, just approving of what he's eating, just makes you feel you're on the right track." Another participant described the feeling he had when the nurse would visit: "When someone is in a positive mood, then it helps you along in a positive mood." Supporting relationships were essential to all aspects of hanging on to hope, connecting with something bigger and stronger was another under girding force.

3.4.6.2   Connecting with Something Bigger and Stronger

The participants identified "connecting with something bigger and stronger"; sometimes alone, sometimes as a couple, or as a family, as giving them strength and purpose, and encouraging them to hang on to hope. Participants approached this process in many different ways such as "having deep, deep beliefs", "simple prayer", "connecting with a higher power," or "something that's larger than yourself" to describe the spiritual energy that kept caregivers "on track". One participant described a family meeting in the hospital: "We prayed together, I felt right from after that." She also said: "I have it inside me…deep, deep beliefs, I think you wouldn't have hope if you didn't have that." A male participant described his method to keep hopeful as: "Simple prayer; before you go to sleep." Another participant's way was: "A small prayer at night…what are we thankful for today…that's a builder."

Participants identified the seeds of hope planted by their families, "my grandmother always had hope, she was a very strong person, she encouraged people." One participant said: "It comes with us when you're children; your mother brings it into you." Another said: "We are all here because somebody cared."

Many participants discussed their connections with nature, "nature is very close, we're fortunate here for the beauty of it." A caregiver who was also a farmer said: "You look forward to sunny day or rain when it comes at just the right time. It would have been a lot worse if this had happened in the wintertime, because it's so dull and dismal, now the first thing you do [every day] is look at how everything is growing."

For some participants connecting with something bigger and stronger meant: "It's just the knowledge that the world is a big place…you find you're looking for a context of some sort that's larger than just you and your problems, that you fit into as one element."

One participant described her belief that connecting with something bigger and stronger gave her hope for the future: "…if things don't turn out the way we hope they will, that God gives us the strength to handle it…that He grants us extra strength so that we can carry on and still have hope for the ones that are left."

Caregivers were able hang on to hope by doing what they had to do, living in the moment, staying positive, and writing their own stories when they had supporting relationships and were able to connect spiritually, finding the larger context for the difficult situations they found themselves in.

3.5 Context for Hanging on to Hope

The context for the basic social process of hanging on to hope began with the devastating news that a loved one was diagnosed with a terminal illness. One participant described it as: "whatever type of cancer or other illnesses that may cause death…it's such a devastating thing that happens." A journey involving the patient and caregiver began with the upsetting change in life circumstances that demanded a transformation in the way they were living their lives.

The family home was the context of the basic social process identified in this study, a setting that allowed them more freedom, normality, and greater access to relationships to build hope processes. The context was different for each caregiver, each relationship, and each family. While at home, the caregivers in this study had support of palliative care teams, coverage of any drugs and supplies, and ongoing monitoring and home support.

Numerous unexpected challenges that arose in the process of care giving provided the impetus to learn ways of hanging on to hope, one participant's mother had received her last rites many times over the last few years, the son still hoped for her to be healthy and live longer; the condition of the patient was a key element in the context.

4   CHAPTER FOUR - DISCUSSION

4.1   The Experience and Processes of Hope

The participants in the study identified "eroding hope" as their main concern related to hope during caregiving for a palliative family member. "Hanging on to hope" was the basic social process used to deal with eroding hope. The sub-processes of hanging on to hope, conceptually illustrated as an upward spiral, were "doing what you have to do", "living in the moment", "staying positive", and "writing your own story." "Supporting relationships" and "connecting with something bigger and stronger" were sub-processes that together directly affected the spiraling sub-processes of hanging on to hope. The findings that have emerged in this grounded theory study are unique when compared to previous research. However, similar individual concepts were found in other research studies with palliative caregivers.

The participants in this study defined hope as the inner strength that gave them the courage and ability to go through a difficult situation; hope was dynamic and a choice. Participants hoped for a comfortable, peaceful, and dignified outcome for the patient, to be able to go through the requirements of caregiving, for time later, and for some, a miracle. This finding is similar to the findings of Herth (1993); Kylmä et al. (2003); and Miettinin et al. (2001). Herth identified hope as dynamic in a mixed methodology study of 25 family caregivers of terminally ill people in the United States. Dynamically fluctuating hope was described by Kylmä et al., in a sample of six

significant others of AIDS/HIV patients in Finland and in a sample of nine bereaved caregivers by Miettinin et al.

Participants described their hopes for an optimal outcome and comfort for the patient. Similar results were found by Martens and Davies (1990) and Proot et al. (2003). Martens and Davies found caregiver hope to be directed toward the patient's comfort in a qualitative grounded theory study with a sample of seven couples. In a qualitative grounded theory design by Proot et al., sampling 13 family caregivers of terminally ill patients at home, realistic hope was described as reducing fear and vulnerability.

The participants in the current study described hope as the inner strength that gave them the courage and ability to go through a difficult situation. This differs from the results of Borneman et al. (2002) and Herth (1993). Both Herth and Borneman et al. defined hope as transcending the current situation. To transcend, according to the Oxford dictionary (Barber, 2004) means to "to go beyond, or to be above", which is different than the experience of the participants who described "going through" a difficult situation. Perhaps this is explained by the use of grounded theory methodology, whereas Herth and Borneman et al. used content analysis of their interview findings. Herth and Borneman et al. administered the Herth Hope Index prior to the interviews which may have increased hope levels and affected the results of the interviews. Purposeful or theoretical sampling was not employed in either study.

4.2   Eroding Hope

The participants in this study described their main concern as eroding hope; bad days, negative messages, and seeing the pain "chipped away" at their hope; however

their hope was always present. This is similar to findings by Kylmä et al. (2003). In this study caregivers experienced the fluctuations of rising towards hope and away from despair and hopelessness. In the current study, the caregivers did not describe feelings of hopelessness, there was always some hope. This could be explained by differences in the samples. Kylmä et al. used caregivers of HIV/AIDS patients, in the current study ninety percent of the caregivers were caring for cancer patients. Social stigma relating to AIDS/HIV may affect caregiver's level of hope. This was also reported by Herth (1993).

The finding of the main concern of "eroding hope" differs from the trajectory of rising hope found by Herth (1993) and Borneman et al. (2002). The qualitative results in Herth's study differed from the reported quantitative measurement of hope. The Herth Hope Index scores for participants in her study increased over time, while qualitatively poorly controlled symptoms, isolation, and concurrent losses were hope-hindering factors. Borneman et al. identified fatigue, anxiety, anger, physical symptoms, and the loss of a cure as interfering with hope. This is comparable to the problem of eroding hope. The mixed methodology used by Herth and Borneman et al. may explain the differences in their findings between the quantitative results of rising hope and the qualitative portion where hope was hindered by the inevitable aspects of care giving.

4.3   Hanging on to Hope

The participants described dealing with eroding hope by hanging on to hope. They defined hanging on to hope as a conscious, active process that required energy, focus, and at times, a fight to not give up hope. This is similar to the Oxford dictionary (Barber, 2004) definition of "hanging on" as "to continue or persevere, especially with difficulty." Hanging on to hope has not been reported as a basic social process by any

58

grounded theory research studies of hope. Other research with caregivers and family members described the concepts of "holding on" (Mok et al., 2003) and "persistence" (Parse, 1999). Mok et al., in a qualitative study of 24 bereaved caregivers of terminally ill patients, identified the initial phase of caregiving involved the process of holding on to hope for a miracle. The Oxford dictionary defines "holding on" as to "keep one's grasp on something" (Barber) while "hanging on" involves persevering through a difficult situation. The difference could be explained by the sample used, as the participants in the research by Mok et al. were bereaved caregivers reflecting back on their experience of caregiving, whereas the sample for the current research was interviewed during the experience of caregiving. Parse described hope as persistently anticipating in a sample of ten family members of patients in long term care facilities. Persistence is similar to the process of "hanging on", however the sample was family members, not caregivers actively providing care.

The findings from these studies suggest that hanging on to hope is a related concept in the experience of caregiving for palliative patients. There are no reported studies that have described the sub-processes of hanging on to hope as doing what you have to do, living in the moment, staying positive, writing your own story, support from others, and connecting spiritually. However, when the sub-processes and their mechanisms are viewed as individual concepts and themes, there are similar findings in the literature.

4.4   Doing What You Have to Do

Caregivers described the ways of "doing what you have to do" as accepting, not giving up, and recharging. Doing what you have to do has not been described in the

research on caregivers. The ways of doing what you have to do, accepting, not giving up, and recharging, have similarities to the findings of other researchers (Herth, 1993; Hudson, 2004; Parse, 1999; Stajduhar & Davies, 1998). Parse identified hope as a resolute perseverance in ten family members of long term care patients, similar to the way of doing what you have to do as "not giving up". The need for recharging or finding personal energy for caregiving was described by Herth, Hudson, and Stajduhar & Davies.

Herth (1993) and Borneman et al. (2002) define hope as "transcending" the experience; a different finding than the current research where caregivers did not identify transcending, rather the process of doing what you have to do was a daily, conscious effort of being there for the patient and not giving up. Herth identified that "doing" was replaced with "being", a process not found in the current research, caregivers did not replace "doing" with "being" however they did use the other sub-processes of living in the moment, staying positive, and writing your own story, in a circular, interchangeable, upward spiral to hang on to hope.

4.5   Living in the Moment

The caregivers in this study used the sub-process of "living in the moment" as they re-focused their thoughts and actions on "the very present." Similar findings have been reported as concepts by Borneman et al. (2002); Davies, Reimer, Brown, & Martens, 1995; Herth, 1993; Martens & Davies, 1990; and Thulesius, Håkansson, & Petersson, 2003. A grounded theory study with 37 formal caregivers of palliative patients by Thulesius et al. identified "living in the present" as a way to regain hope. Hope was the motivation to live a normal life, similar to the finding in the current study

60

of "keeping things normal" as a way of living in the moment. Herth reported a similar finding to "living in the moment" as caregivers used time-refocusing, living one hour or moment at a time, and not looking too far ahead to foster their hope. Borneman et al. identified taking one day at a time as fostering hope.

In this study, caregivers identified knowing what to do and keeping things normal as ways of living in the moment. Other researchers have identified the importance of the concept of normality in the experience of caregiving for palliative patients (Davies et al., 1995; Martens & Davies, 1990; Miettinin et al., 2001; Rose et al., 1997). Davies et al. interviewed 71 family members and found being at home facilitated a sense of normality and sustained relationships. Martens & Davies grounded theory study found the goal of the spouse was to provide a normal life with a positive attitude. Miettinin et al. also identified that maintaining a sense of normalcy in life was experienced by families as still having hope. Normalizing by concentrating on the present was discovered as a coping strategy for caregivers in a study of 21 families with terminally ill members by Rose et al. The process of keeping things normal is important to caregiver's hope as seen from the concurrence of this research with previous research.

4.6   Staying Positive

Caregivers described staying positive as a way to hang on to hope. Staying positive meant looking for the good things in the situation, putting away negatives as much as possible, and appreciating the situation. Similar concepts have been described in previous research (Herth, 1993; Martens & Davies, 1990; Patel, 1996; Taylor, 2003). Herth described cognitive reframing, similar to looking for the good things, and comparative optimizing, similar to comparing to those who have it worse. Caregivers

"hope work" was to remain optimistic (Martens & Davies), similar to the sub-process of staying positive. Patel examined hope-inspiring strategies in 20 spouses of critically ill adults; an optimistic attitude and appreciation for life was a hope strategy, in agreement with staying positive and appreciating the situation in the current study. Taylor related the concepts of positivity, gratitude, and hope to meeting the spiritual needs of family caregivers in a sample of 28 participants. Previous literature supports the process of staying positive as necessary component of the caregiving experience, while hanging on to hope.

4.7   Writing Your Own Story

The participants described hanging on to hope by "writing their own story." Writing your own story was identified as a sub-process at the top of the upward spiral of sub-processes that involved hanging on to hope. This process has not been identified in any previous studies of palliative caregivers. The ways of "writing your own story" were staying in control and making decisions about your future. Similar concepts are evident in the literature in studies by Gelling (1990) and Proot et al. (2003). Gelling found hope in the family of brain-injured patients was assisted by a feeling of control over the situation which allowed family members to formulate and maintain hope, similar to staying in control in the current research. Proot et al. described keeping control decreases the vulnerability which can lead to burnout for caregivers in a study of 13 family caregivers.

4.8   Supporting Relationships

Having supporting relationships with family, friends, and health care professionals emerged as very important to hanging on to hope. This finding is clearly

supported in the literature. The need for connections was identified by Borneman et al. (2002) and Herth (1993) as sustaining relationships were a hope-fostering strategy for caregivers of palliative patients. Relationships as sources of hope were described by Bland and Darlington (2002), Gelling (1999); Parse (1999), and Rose et al. (1997). Family and friends were sources of hope for family members of the mentally ill in a sample of 16 Australians (Bland and Darlington). Rose et al. identified togetherness and partnerships as the most beneficial coping strategies for 21 families caring for a patient with terminal cancer, resulting in a more positive view of the experience of caregiving. Gelling identified relationships as the most important theme in maintaining hope for relatives of head-injured patients. Parse described relationships as essential to hope for family members of patients in long term care facilities. The current research concurs with previous research regarding the essential nature of supportive relationships to the processes of hope for caregivers.

Participants in the current research discussed their experiences with the health care system as either a source of hope or a cause of an erosion of hope. This is similar to the findings of Proot et al. (2003), Strang & Koop (2003), and Mok et al., (2003). Proot et al. found caregivers were vulnerable to fatigue and burnout when they experienced a lack of emotional and informational support from family and health care providers. Strang and Koop, in a study of the caregiving experience for 15 bereaved family members, found supportive networks were both a facilitating and an interfering factor in coping with caregiving. Caregivers depended on support from health care professionals and friends as their most important resource in coping and finding meaning in the situation in the findings of Mok et al. Previous research supports the finding that

relationships greatly affect the experience of caregiving. The current research builds on these findings and adds clarity to the role of support and relationships in the hope experience of caregivers.

4.9   Connecting with Something Bigger and Stronger

The sub-process of connecting with something bigger and stronger was another over-arching sub-process affecting all of the sub-processes of hanging on to hope. Previous research has linked the concepts of hope and spiritual connections in populations of palliative caregivers. In Herth's (1993) study, 92% of the sample of 25 palliative caregivers identified themselves as having a spiritual belief system, which empowered their hope. Borneman et al. (2002) described an "outer source" that enabled caregivers to transcend and found support for hope through faith.

Other researchers examining the experiences of caregivers found that spiritual connections were important to hope (Bland & Darlington, 2002; Kylmä et al., 2003; Patel, 1996; Taylor, 2003). Belief in God constructed hope in caregivers of AIDS/HIV patients (Kylmä et al.), similarly, some caregivers in the current research identified faith as a foundation for hope.

Patel (1996) identified that the most frequently used hope-inspiring strategies of spouses of critically ill adults were spiritual or religious activities. The participants in Patel's sample were experiencing a crisis situation. Similar to the current research, participants identified the spiritual activity of connecting to something bigger and stronger as a way of hanging on to hope. In a sample of 16 family members of people with mental illness, spiritual beliefs were a source of hope (Bland & Darlington, 2002). Taylor (2003) examined spiritual needs of 28 patients with cancer and family caregivers.

64

The need for positivity, hope, and gratitude was identified as a spiritual need of both patients and caregivers. Similarly, the relationship between hope and spirituality is ongoing and reciprocal in the current research. Fifty percent of the caregivers in the current study identified themselves as having no religious preference, however, spiritual connections to God, faith, nature, and other elements emerged as a process.

4.10 Discussion Summary

The findings of the current research are unique. By interviewing caregivers during caregiving and using grounded theory methodology, the main concern of eroding hope and the basic social process of hanging on to hope emerged from the data. These processes have not been previously identified in research with palliative caregivers or in hope research with other caregivers.

The research has attempted to capture the inner workings of hope for palliative caregivers going through a difficult situation. The sub-processes of hanging on to hope have been theoretically linked into a model that resembles an upward spiral, picturing the upward momentum of hope that caregivers were able to achieve using the sub-processes of hanging on to hope. The findings of this study have the potential to influence the care and support offered to palliative caregivers and provides a contribution to practice, education, and research.

4.11 Factors Influencing the Study

There were several factors influencing this study due to the sample characteristics, context of the study, and the methodology. The sample was from two urban centers in Saskatchewan, Canada. Both cities have palliative care programs, providing care and support for palliative patients. The findings reflect the similar

processes of the hope experience for the sample; qualitatively the findings were the same across the two cities used in this study. Sampling began in Prince Albert and was concluded in Saskatoon, confirming the consistency of the results across the two sites.

Half of the participants were either Protestant or Catholic and the other half had no religious preference. Religious affiliation and ethnicity may have influenced the results of the study. The participants were English speaking, which limited the possible inclusion of participants who did not speak English. The sample was also limited to individuals available and willing to participate in the study. Caregivers who were too busy, or too stressed, or not interested in speaking to a researcher about hope were not included in the study. Saturation was reached with ten participants. According to Glaser (2001) the small sample size is not a concern as long as saturation of the categories is achieved.

Context, the condition in which the concepts occur, (Glaser, 1992), may also have been a limitation of the study. Participants were providing care within their homes for a family member with a life-threatening condition, usually being visited by a palliative care team and receiving palliative care services. The description of their hope experience was within the context of the patient's condition and symptoms, the unpredictability of their daily lives, frequent challenges and stressors, and dealing with end of life issues.

The grounded theory developed in this research is a reflection of the participants' personal experiences. The readers need to make their own conclusions as to whether the theory has relevance and fit into similar situations as it is applied in practice.

5   IMPLICATIONS FOR PRACTICE AND RESEARCH

The results of this study add insight and perspective into the complexities of human existence and societal relationships. The ultimate goal of this research endeavor was to enhance the effectiveness, efficiency, and compassion of day to day work with palliative caregivers, providing tools that will enrich the experience of palliative care, encouraging caregivers to potentially transform a difficult situation into one of strength and growth. The grounded theory developed by this qualitative research provides opportunity for reflection on personal practice as well as needs within the health care system; the readers of these research results will verify if the theory is generalizable or transferable to their own practice setting. The results of implementing this grounded theory into practice may be informal or structured. Practical suggestions for how this theory could be implemented into practice with caregivers will be followed by ideas for future research including theory development and the building of interventions for caregivers that could be tested for effectiveness.

5.1   Implications for Practice

A palliative home care nurse commented: "I don't always know what to say to the caregivers I encounter in my day to day work" (G. Haubrich, personal communication, July 12, 2004). Even experienced health care professionals may feel unsure of how to handle the variety of stressful and difficult family situations they walk into and become a part of on a daily basis. The results of this research may be helpful to

67

the professional, as the ways of hanging on to hope, its processes and sub-processes can be applied to daily practice situations.

For example, paying attention to the caregivers' experience of hope and appreciating the value of hope to the caregiver is a big first step towards assisting families to get through the palliative care experience. The informal caregivers in this study defined hope as inner strength that gave them the courage and ability to go through a difficult situation. It was dynamic and a choice. Their main concern was eroding hope. Being aware of the caregiver's need for hope in every interaction with health care professionals may prevent an unnecessary erosion of hope. When talking to caregivers, inquire about their feelings of hope, reassuring them that the fluctuations in the level of hope are part of the experience for many caregivers. Recognizing the impact of bad days, negative messages, and seeing the pain on the level of hope can be mitigated by providing support and practical strategies that encourage caregivers to hang on to hope. The health and well being of the caregiver is essential to providing palliative care at home. Assessment and monitoring of caregivers, who are at risk of eroding hope, will ensure their ability to provide care that both the patient and the family wish to have; as comfortable, dignified and normal as possible, remaining within the home setting if possible.

The caregivers in this research hoped to be able to do a good job of caregiving. This can be facilitated by providing reassurance, information, and the equipment that may be needed to do a good job. Recognizing and reinforcing the processes of doing what they have to do, living in the moment, staying positive, and writing their own story, practical ways for each of these sub-processes could be put into practice. Giving

positive reinforcement of their abilities to use hope strategies allows caregivers to build their own strengths and resources to solve their own problems and transform a difficult experience into a positive time of growth.

Caregivers need to know what to do, who to call, general and specific information given at the right time, reassurance, and positive messages. Paying attention to the caregiver's need for recharging, including respite to allow them to feel in control of their own circumstances, will keep them going through difficult days. An ongoing attentiveness to the processes of hope will offer optimally effective encouragement and support. Living in the moment is a strategy that can be identified, discussed, and reinforced. In practice, arriving at the home of the patient and caregiver, a positive approach to the situation will affect the caregiver. Helping the caregiver to look for the positives in any circumstance and teaching caregivers the skill of putting away negative thoughts, will assist them to stay positive and prevent the situation from breaking down.

Writing your own story can be encouraged by giving options to families, working with them to understand their values, priorities, and wishes, giving them more control in a difficult situation. Encourage them to choose the best options for the situation; palliative care provides many options, services, and opportunities to improve quality of life.

Caregivers need to be encouraged to make the most of every opportunity for family closeness and relationship building, sometimes just by "talking about it" getting fears and issues out into the open; offer counseling for families. Encourage family meetings, provide a facilitator to ensure everyone gets heard and a line of communication is established. Connecting to something bigger and stronger should be

encouraged, looking at their situation within a larger context can bring a reassuring comfort and foster hope. Fostering and encouraging hope is an essential component of providing holistic nursing care to families. Families need to be provided with the opportunity to make the most of their remaining time together by applying the knowledge gained about the processes of hope for caregivers. Having support from organizational and administrative levels of the health care system would improve the application of this research into practice. Also needed is the ongoing education of health care professionals to be sensitive to the hope of caregivers. Education is needed to provide professionals with the tools and resources to be able to apply the processes of hope in their daily clinical practice with caregivers.

5.2   Implications for research

Ongoing research is needed to develop our knowledge base of the experience of hope for caregivers. By addressing the limitations of the study, research questions arise: What is the hope experience of caregivers who are of specific cultural groups or religious backgrounds than those in the current study? What is the hope experience of caregivers of patients with diseases other than cancer? What is the experience of hope for informal caregivers providing care in rural or remote areas? Does the type and amount of health services provided in a setting have an influence on hope? A study of the hope experience at different aspects of the caregiving trajectory such as early diagnosis, transition to palliative care, or caregivers in bereavement, could be examined in future research. The use of other qualitative and quantitative methodologies would address the limitations of the study results.

Research to test the theory would add to the development of a middle-range theory, useful to practice; research is needed to test and refine this grounded theory. Specific interventions for caregivers can be developed and tested based on the findings of this study.

5.3   Closing Thoughts

The results of this study are a product of the willingness of expert caregivers to share their experiences with a nurse researcher and a tribute to the strengths and resourcefulness of those caregivers who have developed effective hope strategies that enable them to go through a difficult life challenge. Much can be learned from these experts, those with an insider's view of the experience. Supporting caregivers as they hang on to hope is an essential aspect of providing compassionate and effective care to families going through the experience of palliative care. As Cicely Saunders (Saunders & Sykes, 1993), the founder of palliative care teaches: "For the family we have to be aware of the whole group and the understanding and support they need if they are to find and use their own resources and strengths" (p. 9).

REFERENCES

Aranda, S. (2001). Caregiving in advanced cancer lay decision making. *Journal of Palliative Care, 17(4),* 270-276.

Barber, K. (Ed.). (2004). *Canadian Oxford dictionary* (2nd ed.) Ontario, Canada: Oxford University Press.

Beach, D. L. (1995). Caregiver discourse: Perceptions of illness-related dialogue. *The Hospice Journal, 10 (3),* 13-25.

Bland, R., & Darlington, Y. (2002). The nature and sources of hope: Perspectives of family caregivers of people with serious mental illness. *Perspectives in Psychiatric Care, 38(2),* 61-68.

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

Bonanno, G. A., Wortman, C. B., Lehman, D. R., Tweed, R. G., Haring, M., Sonnega, J., et al. (2002). Resilience to loss and chronic grief: A prospective study from preloss to 18-months postloss. *Journal of Personality and Social Psychology, 83,* 1150-1164.

Borneman, T., Stahl, C., Ferrell, B. R., Smith, D. (2002). The concept of hope in family caregivers of patients at home. *Journal of Hospice and Palliative Nursing, 4* (1), 21-33.

Brink, P. J., & Wood, M. J. (2001). *Basic steps in planning nursing research: From question to proposal.* (5th Ed.) Sudbury, MA: Jones and Bartlett Publishers.

Brown, P., Davies, B., & Martens, N. (1990). Families in supportive care. Part II: Palliative care at home: viable care setting. *Journal of Palliative Care, 6(3),* 21-

27.

Burns, N., & Grove, S. K. (2001). *The practice of nursing research (4th Ed.).*
Philadelphia: W. B. Saunders Co.

Canadian Hospice Palliative Care Association. (2001). *Brief to the commission on the*
future of health care in Canada. Retrieved October 15, 2003 from:
http://www.chpca.net/pub_and_press_releases/romanow_commission/CHPCA_B
rief.PDF

Canadian Palliative Care Association. (March 31, 1999). *Canadian agenda for research*
in palliative care. Retrieved October 28, 2003 from
http://www.chpca.net/committees/research/Canadian_Research_Agenda.PDF

Chapman, K. J., & Pepler, C. N. (1998). Coping, hope, and anticipatory grief in family
members in palliative home care. *Cancer Nursing, 21,* 226-234.

Charmaz, K. (2000). Grounded theory: Objectivist and Constructivist Methods. In N. K.
Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp.509-535).
Thousand Oaks, CA: Sage Publications, Inc.

Chiverton, E. (1997). Social support within the context of life-threatening illness.
International Journal of Palliative Nursing, 3(2), 107-110.

Commission on the Future of Health Care in Canada. (2002). *Building on values: The*
future of health care in Canada-Final report. [Commissioner Roy J. Romanow].
Saskatoon, SK: Commission on the Future of Health Care in Canada.

Davies, B., Reimer, J. C., Brown, P., & Martens, N. (1995). *Fading away: The*
experience of transition in families with terminal illness. Amityville, NY:
Baywood Publishing Co.

Davis, B. D., Cowley, S. A., & Ryland, R. K. (1996). The effects of terminal illness on

    patients and their carers. *Journal of Advanced Nursing, 23,* 512-520.

Dawson, S., & Kristjanson, L. J. (2003). Mapping the journey: Family carer's

    perceptions of issues related to end-stage care of individuals with muscular

    dystrophy or motor neurone disease. *Journal of Palliative Care, 19(1),* 36-42.

Denzin, N. K., & Lincoln, Y. S. (Eds.). (2000). *Handbook of qualitative research.*

    Thousand Oaks, CA: Sage Publications, Inc.

Duggleby, W. (2000). Enduring suffering: A grounded theory analysis of the pain

    experience of elderly hospice patients with cancer. *Oncology Nursing Forum,*

    27, 825-830.

Duke, S. (1998). An exploration of anticipatory grief: The lived experience of people

    during their spouses' terminal illness and in bereavement. *Journal of Advanced*

    Nursing, 28, 829-839.

Enyert, G., & Burman, M. E. (1999). A qualitative study of self-transcendence in

    caregivers of terminally ill patients. *American Journal of Hospice and Palliative*

    Care, 16, 455-462.

Fakhoury, W. K. H., McCarthy, M., & Addington-Hall, J. (1997). Carer's health status:

    Is it associated with their evaluation of quality of palliative care? *Scandinavian*

    Journal of Social Medicine, 25(4), 298-301.

Farran, C. J., Herth, K. A., & Popovich, J. M. (1995). *Hope and hopelessness: Critical*

    clinical constructs. Thousand Oaks, CA: Sage Publications, Inc.

Gelling, L. (1999). The experience of hope for the relatives of head injured patients

    admitted to a neurosciences critical care unit: a phenomenological study.

Nursing in Critical Care, 4, 214-221.

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

Glaser, B. G. (1992). *Basics of grounded theory analysis: Emergence vs. forcing.* Mill Valley, CA: Sociology Press.

Glaser, B. G. (2001). *The grounded theory perspective: Conceptualization contrasted with description.* Mill Valley, CA: Sociology Press.

Goldstein, N. E., Concato, J., Fried, T. R., Kasl, S. V., Johnson-Hurzeler, R., & Bradley, E. H. (2004). Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *Journal of Palliative Care, 20(1),* 38-43.

Herth, K. (1993). Hope in the family caregiver of terminally ill people. *Journal of Advanced Nursing, 18,* 538-548.

Hudson, P., Aranda, S., & McMurray, N. (2002). Intervention development for enhanced lay palliative caregiver support: The use of focus groups. *European Journal of Cancer Care, 11,* 262-270.

Hudson, P. (2004). Positive aspects and challenges associated with caring for a dying relative at home. *International Journal of Palliative Nursing, 10(2),* 58-64.

Hull, M. M. (1990). Sources of stress for hospice caregiving families. In J. M. Kirschling (Ed.) *Family-based palliative care* (pp. 29-54). New York: Haworth Press, Inc.

Irvin, B. L., & Acton, G. J. (1997). Stress, hope, and well-being of women caring for family members with Alzheimer's disease. *Holistic Nursing Practice, 11*(2), 69-80.

King, N., Bell, D., & Thomas, K. (2004). Family carer's experiences of out-of-hours

    community palliative care: A qualitative study. *International Journal of*

    Palliative Nursing, 10(2), 76-83.

Kristjanson, L. J., Sloan, J. A., Dudgeon, D., & Adaskin, E. (1996). Family members'

    perceptions of palliative cancer care: Predictors of family functioning and family

    members' health. *Journal of Palliative Care, 12 (4),* 10-20.

Kristjanson, L. J., Leis, A., Koop, P. M., Carriere, K. C., Mueller, B. (1997). Family

    members' care expectations, care perceptions, and satisfaction with advanced

    cancer care: Results of a multi-site pilot study. *Journal of Palliative Care, 13(4),*

    5-13.

Kylmä, J., Vehviläinen-Julkunen, K., & Lähdevirta, J. (2003). Dynamics of hope in

    HIV/AIDS affected people: An exploration of significant others' experiences.

    Research and Theory for Nursing Practice: An International Journal, 17, 191-

    205.

LoBiondo-Wood, G., & Haber, J. (2002). *Nursing research: Methods, critical*

    appraisal, and utilization. (5th Ed.). St. Louis, MI: Mosby-Year Book, Inc.

Martens, N., & Davies, B. (1990). The work of patients and spouses in managing

    advanced cancer at home. In J. M. Kirschling (Ed.) *Family-based palliative care*

    (pp. 55-73). New York: Haworth Press, Inc. Also published in *The Hospice*

    Journal, 6 (2).

Miettinin, T., Alaviuhkola, H., & Pietila, A. (2001). The contribution of "good"

    palliative care to quality of life in dying patients: Family members' perceptions.

    Journal of Family Nursing, 7(3), 261-280.

Mok, E., Chan, F., Chan, V., & Yeung, E. (2003). Family experience caring for

   terminally ill patients with cancer in Hong Kong. *Cancer Nursing, 26(4),* 267-

   275.

Morse, J. M., & Field, P. A. (1995). *Qualitative research methods for health*

   professionals (2nd Ed.). Thousand Oaks, CA: Sage Publications.

Morse, J. M., & Richards, L. (2002). *Readme first for a user's guide to qualitative*

   methods. Thousand Oaks, CA: Sage Publications, Inc.

Oldham, L., & Kristjanson, L. J. (2004). Development of a pain management

   programme for family carers of advanced cancer patients. *International Journal*

   of Palliative Nursing, 10(2), 91-99.

Parse, R. R. (1999). The lived experience of hope for family members of persons living

   in a Canadian chronic care facility. In R. R. Parse (Ed.), *Hope: An international*

   human becoming perspective (pp. 63-77). Sudbury, Mass: Jones & Bartlett.

Patel, C. T. C. (1996). Hope-inspiring strategies of spouses of critically ill adults.

   Journal of Holistic Nursing, 14(1), 44-65.

Pinch, W. J. (1995). Synthesis: Implementing a complex process. *Nurse Educator, 20*

   (1), 34-40.

Proot, I. M., Abu-Saad, H. H., Crebolder, H. F. J. M., Goldsteen, M., Luker, K. A., &

   Widdershoven, G. A. M. (2003). Vulnerability of family caregivers in terminal

   palliative care at home: Balancing between burden and capacity. *Scandinavian*

   Journal of Caring Sciences, 17, 113-121.

Rhodes, P., & Shaw S. (1999). Informal care and terminal illness. *Health and Social*

   Care in the Community, 7(1), 39-50.

Rollison, B., & Carlsson, M. (2002). Evaluation of advanced home care: The next-of-kin's experiences. *European Journal of Oncology Nursing, 6(2),* 100-106.

Rose, K. (1997). How informal carers cope with terminal cancer. *Nursing Standard, 11(30),* 39-42.

Rose, K. E. (1998). Perceptions related to time in a qualitative study of informal carers of terminally ill cancer patients. *Journal of Clinical Nursing, 7,* 343-350.

Rose, K. E., Webb, C., & Waters, K. (1997). Coping strategies employed by informal carers of terminally ill cancer patients. *Journal of Cancer Nursing, 1(3),* 126-133.

Sandelowski, M., & Barroso, J. (2003). Classifying the findings in qualitative research. *Qualitative Health Research, 13,* 905-923.

Saunders, C. & Sykes, N. (Eds.) (1993). *The management of terminal malignant disease.* London: Edward Arnold.

Sherwood, P. R., Given, B. A., Doorenbos, A. Z., & Given, C. W. (2004). Forgotten voices: Lessons from bereaved caregivers of persons with a brain tumor. *International Journal of Palliative Nursing, 10(2),* 67-75.

Speziale, H. J. S., & Carpenter, D. R. (Eds.) (2003) *Qualitative research in nursing: Advancing the humanistic imperative.* (3rd Ed.). Philadelphia: Lippincott Williams & Wilkins.

Stajduhar, K. I., & Davies, B. (1998). Palliative care at home: Reflections on HIV/AIDS family caregiving experiences. *Journal of Palliative Care, 14(2),* 14-22.

Stajduhar, K. I. (2003). Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care, 19(1),* 27-35.

Staples, P., & Jeffrey, J. (1997). Quality of life, hope, and uncertainty of cardiac patients and their spouses before coronary artery bypass surgery. *Canadian Journal of Cardiovascular Nursing, 8(1),* 7-15.

Steele, R. G., & Fitch, M. I. (1996). Coping strategies of family caregivers of home hospice patients with cancer. *Oncology Nursing Forum, 23,* 955-960.

Stetz, K. M. (1987). Caregiving demands during advanced cancer: The spouse's needs. *Cancer Nursing, 10(5),* 260-268.

Strang, V. R., & Koop, P. M. (2003). Factors which influence coping: Home-based family caregiving of persons with advanced cancer. *Journal of Palliative Care, 19(2),* 107-114.

Taylor, E. J. (2003). Spiritual needs of patients with cancer and family caregivers. *Cancer Nursing, 26(4),* 260-266.

Thulesius, H., Håkansson, A., & Petersson, K. (2003). Balancing: A basic process in end-of-life cancer care. *Qualitative Health Research, 13,* 1353-1377.

Willert, M. G., Beckwith, B. E., Holm, J. E., & Beckwith, S.K. (1995). A preliminary study of the impact of terminal illness on spouses: Social support and coping strategies. *The Hospice Journal, 10(4),* 35-47.

World Health Organization. (2003). *WHO definition of palliative care.* [Electronic version]. Retrieved November 15, 2003 from http://www.who.int/cancer/palliative/definition/en/

Yates, P., & Stetz, K. M. (1999). Families' awareness of and response to dying. *Oncology Nursing Forum, 26(1),* 113-120.

APPENDIX A Table of Research with Palliative Caregivers

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
Aranda (2001)	Report from a larger study of community-based palliative care programs. How a group of lay carers made the decision to provide home palliative care to a relative with cancer.	25 lay caregivers from 2 community services, Australia.	Exploratory, qualitative data, interviews in the carer's home.	Interviews taped, transcribed, coded, thematic and content analysis.	Themes were "who decides", obligation. "Decision type" natural/normal and the automatic/implicit. Decision arose out of social and emotional bonds.	Decisions to provide care based on pre-existing relationships with the dying person, influenced by the personal, social, and material circumstances. Significant personal cost, need for greater awareness of the decision making process and the needs of the caregivers.	A needs survey with some thematic effort to transform the data. Identifying practical themes that assist practice.
Beach (1995)	Examine communication patterns of family caregivers, identify dysfunctional patterns.	10 family caregivers, spouse or child of a terminally ill patient. 80% female, 8 Caucasian, 2 African-American, USA.	Qualitative, descriptive, content analysis to identify and describe the communicative experiences of family caregivers, re death, denial, bereavement. Home setting for the interviews.	Semi-structured interviews.	Caregiver denial via communication avoidance strategies, patient denial. One couple had discussed arrangements, this caregiver felt stronger in bereavement.	Communication not open, more stilted with terminal diagnosis than prior, need for identification of teaching/training needs of families.	Rigor involved audit trail, credibility, and fittingness with other caregivers and other health care workers. Sampling not purposive or theoretical. Lack of methodological framework. Survey of needs, no new theory.
Bonanno et al. (2002)	To examine patterns of grief and their antecedent predictors; resilience, chronic grief, absence of grief, delayed grief, qualities of the	Prospective sample of 1532 married individuals, husband age 65 or older, 2-hour interview. Obituaries used to identify loss of a spouse,	See sample, design is prospective, preloss predictor variables included qualities of the marriage, interpersonal dependency, avoidant/dismissive attachment,	Center for Epidemiologic Studies Depression Scale, Bereavement Index, Present Feelings About Loss Scale, Texas Revised Inventory of Grief, many	Identification of 5 core bereavement patterns; common grief, chronic grief, chronic depression, and improvement during bereavement, and resilience. Resilient pattern most	Clearest predictor of chronic grief was dependency, chronic depression. Resilient pattern the most common, displayed a lack of grief reactions due to their coping resources. Delayed grief not found. Chronic depression and	Average age of participants was 72, cannot be generalized to a younger population, however most grief occurs in this age group. Changes in perceptions occur after bereavement, the

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
	conjugal relationship, coping, meaning, and context.	invited for a follow-up interview at 6 months and 18 months postloss. 205 individuals were able to participate in both interviews. Detroit, USA.	interpersonal comfort, coping resources, religiosity, world view, and context such as caregiving strain, and perceived support.	other scales, interviewer observations.	frequent, chronic grief associated with preloss dependency and resilience with preloss acceptance of death and belief in a just world.	chronic grief had the most symptoms over the 18-month trajectory. Caregivers with high strain levels were less likely to be depressed, grieving at 18 months, were in the resilient category.	data reveal patterns, new explanations of resilience, chronic depression and chronic grief. Quantitative measures paired with interviewer observations add rigor to the findings.
Brown, Davies, & Martens (1990)	To find out from the family members and the patient, the location of care they preferred and why.	24 family members interviewed, Canada.	Qualitative.	Interviews taped, transcribed, content analysis and constant comparative analyses (Glaser and Strauss).	Preference for care at home over institution. Reasons were being there, normalcy, self-determination, reciprocity, and sustaining relationships.	Factors determining choice were caregiver availability and ability, isolation, fatigue, role overload, nature of the home care services, patient's physical status.	Good description of the research, some development of themes in the data, no conceptualizing. Positive and negative overview, balanced approach.
Chiverton (1997)	To explore the subjective experience of primary carers in palliative care with a view to explore what comprises social support.	4 carers of spouses, UK.	Pilot study, qualitative, sociological inquiry, to explain and understand the social phenomena related to the social organization of dying.	Unstructured interviews, taped, home setting, observation chart for 2 weeks to keep track of the length and purpose of visits and telephone calls.	Trajectory, the downhill course with occasional improvements. The burden of care, the work involved organization of care, emotional labor. Keeping going.	Helping and sustaining behaviours appropriate to the complex and uncertain demands of the caring role are essential for social support.	Lots of detail about the 4 participants (? confidentiality issues) Data conceptualized and related to previous findings and the literature.
Davies, Reimer, Brown, & Martens (1995)	Examine the transition of "fading away" as families confront terminal illness in a member.	23 families, patient and spouse and children, total 71 family members,	Qualitative, grounded theory, prospective approach documenting the families'	Family interviews.	Concept of "transition" and "fading away" identified as redefining, burdening,	Practical suggestions presented from the point of view of patient, spouse, and children, focus on interventions that will bring a positive	Asking the families themselves. Methodology outlined and detailed, ensuring rigor. "Fading away" and themes identified;

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
		Canada.	experiences.		struggling with paradox, contending with change, searching for meaning, living day-to-day, preparing for death. Adjustment of reality for entire family.	outcome. Challenges detailed of research with families in a palliative care situation.	linkages unclear.
Davis, Cowley, & Ryland (1996)	To identify and assess the needs of terminally ill patients, relatives and carers.	56 bereaved carers, UK.	Qualitative interviews.	Semi structured interviews.	Hard to obtain a diagnosis of terminality, a slow, distressing, and painful period.	Need for earlier diagnosis and referrals, access to services.	Lack of scientific rigor. A needs assessment, topical survey, organized into themes.
Dawson & Kristjanson (2003)	To examine the perceived needs of carers during the final stage of caring for someone with muscular dystrophy.	16 carers of persons with MD, 10 current and 6 bereaved, 3 individuals with MD and health professionals also interviewed. Australia.	Exploratory, qualitative, use of a reference group of health professionals and experts in MD to assist with sampling, interview design, synthesis.	In-depth interviews audio taped and transcribed, content analysis and constant comparison techniques, coding.	Palliative model useful, uncertainty, loss, "health system crossing points", living with limits, "reaching forward", hoping for a miracle cure, learning from other carers, planning.	MD not usually considered under palliative care model, issues of transition, uncertainty, access.	Description of the research process, reference group, data saturation, identification of themes. Findings not conceptualized or related to the literature as themes emerged. More of a needs assessment, survey.
Duke (1998)	Exploration of anticipatory grief during a spouses' terminal illness and in bereavement.	4 bereaved spouses in the second year after the death of a terminal malignant disease, England UK.	Heideggerian phenomenological approach, evaluated using criteria identified by Madison.	Unstructured interviews, taped, transcribed, verified, analyzed using hermeneutics.	Thematic map of the experiences during spouse illness and bereavement. Roles changed, increasing physical caregiving, being in	Anticipatory grief not a preparation for the bereavement, value of social support to mitigate stress, collecting and constructing memories, continual change in roles, social expectations, but	Excellent description of conceptual base for the study, overt explanations of the research process, adding scientific rigor. Results discussed in relation

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
					suspense, putting life on hold, crisis, importance of memories, symbols of the experience, and "memories as treasure".	all participants reported they derived comfort in their bereavement fro m having been a caregiver.	to the literature. Conceptual/thematic description of the data, lack of a central point or thesis.
Enyert & Burman (1999)	To assess the caregiver's sense of emotional well being and their ability to transcend and find meaning in the caregiving experience.	7 Caregivers of a family member who had died 6 to 12 months prior to the interview. USA.	Qualitative combination of ethnographic techniques and grounded theory.	Unstructured interviews, audio taped, conducted in the home of caregivers.	Perspective, what the caregiver had done was meaningful to them, in spite of hardship. Support networks, caregiving action, lack of training. There was ongoing grief, fatigue, many challenges. Processes of "being with" and "doing for" emerged, and a commitment to the task.	All participants identified a positive aspect to the experience, either during or after the death of the loved one. Caregiving was difficult but overwhelmingly meaningful, most able to find transcendence.	Bereaved participants may have arrived at transcendence after the experience, not during. Very good description of the methodology, trustworthiness. Results as themes, and processes, with sub processes, related to participant quotes. Practical article to apply to care of families and caregivers.
Fakhoury, McCarthy, & Addington-Hall (1997)	Exploring the relationship between carer's health after the patient's death and their perceptions of the quality of care delivered to these patients over the last 12	Total in original study 3969, random sub sample of 1858 bereaved (by 10 months) informal carers of cancer patients, UK.	Retrospective, Satisfaction of care and health indicators or self-rating, psychological functioning, adjustment to bereavement, experience of bereavement health	Statistical analysis of questionnaire, measures of association.	Association between bereaved carer's health status, psychologically functioning, the experience of bereavement health problems, and their satisfaction with services of	Satisfaction may be linked to a positive attitude, predisposes to good bereavement outcomes. Contentment, rather than discontent with the services in the past may be the result of a positive experience of bereavement.	Associations not able to make causal links. Questionnaires subjective, difficult to recall situation of receiving care. Outcomes not useful for practice or program evaluation.

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
	months of life.		problems.		palliative care.		
Goldstein et al. (2004)	To identify factors associated with caregiver burden among those caring for terminally ill patients with cancer.	Primary caregivers of patients with cancer, in a hospice program, 76 caregivers interviewed prior to the death of the patient, 130 within one month of the death of the patient. USA.	Cross-sectional study of interviews, survey of socioeconomic situation, burden of care, quantitative analysis of results.	Social Network Index, Zarit Burden Inventory.	No association between timing of interview and the outcome measure, ie whether the interview was before or right after the death of the patient. Overall caregiver burden related to more restrictions in activities, younger age of caregiver, not related to the actual activities performed.	Need to consider impact of the caregiver, social support system and restrictions in activity. Need for social networks. More burden for caregivers caring for parents.	Good description of statistical procedures, decisions. Related results to other research, important to consider when developing care plans for families, and appropriate interventions.
Hudson (2004)	To explore the challenges and positive aspects associated with supporting a relative or friend dying of cancer at home.	47 family caregivers of advanced cancer patients who had recently commenced home palliative care. Australia.	This qualitative study part of a larger randomized controlled trial.	Semi structured interviews, data handwritten, typed into an electronic database and analyzed using line by line and thematic analysis.	Challenges include own health, family, insufficient skills, time, inadequate support, 60% able to identify positive aspects, 40% unable to identify any positive aspects.	Need for interventions that would assist finding positive aspects, must be aware of the challenges of caregiving. Planned and systematic approach to supporting family caregivers needed, more structured approaches to family care.	Non-theoretical sampling, topical survey inventory approach. Some attempt to identify themes, not connected to each other.
Hudson, Aranda, & McMurray (2002)	Exploration to assist in the development of a nursing intervention to enhance the guidance and	3 groups, bereaved lay caregivers, lay caregivers currently providing palliative care at	First phase of 3, qualitative studies to gather data, focus groups, with both past and present issues.	Demographic questionnaire, discussion guide for the focus groups, moderator and assistant.	Caregivers identified support from the palliative team, previous experience, relationship with dying person, and	Information for caregivers included steps to promote encouragement/optimism, potential positive aspects of caregiving, preparing for bereavement.	Careful and detailed description of the data gathering process, lend rigor to the study. Lists generated of fundamental needs, topical survey style,

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
	support provided to lay caregivers of persons dying of cancer at home.	home, and community palliative care nurses, 8 for each group recruited. Australia.			taking one day at a time, looking for the light at the end of the tunnel, burden of caregiving.		and no conceptual or interpretive analysis.
Hull (1990)	To identify the concerns and stresses families encounter in palliative caregiving at home.	14 family members from 10 families, USA.	Qualitative, Glaser's grounded theory, longitudinal, final interview after death of patient, 55 visits over 16 months.	Semi-structured interviews, at homes of family caregivers.	Three areas of stress identified; patient symptoms (meds, bowel/bladder, etc.), interactions with others, and concerns for self, especially guilt.	Guilt; light at then end of the tunnel would go off and on, guilt before death was denied after the death. Reflection after death was on the whole experience; were more satisfied with their performance as caregivers.	Good descriptions of methods, scientific rigor, credibility, fittingness, auditability, and confirmabiliy. Recommendations for research include exploring the meaning of the experience and ways to cope. Findings not theorized, just listed.
King, Bell, & Thomas (2004)	Explore carers' experiences of out-of-hours community palliative care and services.	15 Bereaved family carers who had received palliative care at home, UK.	Qualitative.	Semi structured interviews, in the home, thematic analysis.	Crisis contact information, quality out-of-hours care and support, drugs and equipment, use of handover forms.	Necessity of providing good, clear information about sources of support, communication needs.	Description of data, retelling of stories as findings. No attempt to build on prior knowledge or the literature.
Kristjanson, Leis, Koop, Carriere, & Mueller (1997)	To evaluate psychometric properties of assessment tools, family members' care expectations; care perceptions, and satisfaction	72 family members drawn equally from medical hospital units, palliative care units, home care programs in Alberta, Saskatchewan,	Multi-site pilot study. Discrepancy theory as framework, correlational and causal modeling. Field notes for content analysis.	F-Care Expectations Scale, F-Care Perceptions Scale, FAMCARE Scale, and the General Functioning Scale of the Family	All 4 tools gave acceptable reliability estimates. Discrepancy theory predicted family care satisfaction.	As the discrepancy between care expectations and care perceptions increased, care satisfaction decreased. Longer care trajectory increased satisfaction. May predict bereavement outcomes. Importance of	Quantitative study of complex family relationships, tools to measure satisfaction. Not possible to be scientifically rigorous with the population involved. Limited application to nursing

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
	with advanced cancer care.	and Manitoba, Canada.		Assessment Device, demographic form.		family care.	practice, more to administration review of service provision and ongoing research.
Kristjanson, Sloan, Dudgeon, & Adaskin (1996).	To examine family members' care experiences as predictors of family health and functioning during the palliative care phase (T1) and 3 months following death (T2) of the patient.	Consecutive sample of 80 family caregivers of advanced cancer patients, admitted to a hospital unit, at T1. Sample of 64 at T2, Canada.	Correlational design, causal modeling, QOL and care satisfaction (Need Fulfillment and Discrepancy Theories) and to examine predictors of care satisfaction and bereavement outcomes.	Symptom distress scale, quality of life scale collected from palliative patient, 7 instruments used for family member.	Discrepancy theory at T1 found to predict family care satisfaction at T2. Symptom distress lowered QOL scores for patients and families. Poor family functioning at T1 correlated with T2, esp. mental health.	Need to care for family as a unit, correlation of symptoms and QOL, including into bereavement. Need for assessment and intervention of patient and family needs. Multiple testing, vulnerable populations.	Difficult to quantify outcomes, numerically demonstrates what qualitative studies do with added meaning. Gives further incentive to study QOL and coping to gain understanding of family functioning.
Martens & Davies (1990)	To describe the resources identified by patients and spouses to manage advanced cancer care at home and to describe a conceptualization of resource use as "work."	Seven couples, over 45 years of age, spouse as caregiver, from 2 outpatient clinics, Western Canada.	Qualitative, Glaser's grounded theory, semi-structured interviews, in the home setting, each member of the couple interviewed twice alone. Then together end of second interview.	Interview guide, transcripts, field notes, and diary notations.	Faith, attitude, relationships. Caregivers not as self-reflective as the patients. Uncertainty, inevitability of death, appearing optimistic. Work of patients and spouses, "hoping" identified as a type of work, for both pt and spouse.	Hope changed through the experience; seeking a cure, comfort, then short-term goals and spiritual re-unity. Main resource identified as internal for the patient and external for the spouse. "Work" required energy and focus involved courage and will. Identification of unique role of caregiver in the family system.	Detailed description of method, paper trail, enhancing rigor, Caucasian couples only. Clarifies what it means to provide emotional support to facilitate coping of caregiver and family. Valuable and useful findings, describing concepts and themes more clearly.
Miettinin, Alaviuhkola, & Pietila (2001)	Examine the perceptions of family members about the elements of	9 relatives, one year after patient's deaths, 3 deaths were at home, not all	Qualitative, interpretative, phenomenography, how the care and QOL appeared to	Interviews unstructured, to describe good QOL of patients and good	Meaningful units included living a normal life, hope, spiritual strength, honest information.	Importance of family issues, valuing family involvement, good QOL involved living a normal, enjoyable life in their	Open discussion of the rigor of the research, validity, trustworthiness, and auditability,

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
	palliative care valuable to ensure quality of life for palliative patients.	caregivers, purposive sampling. Finland.	family members, interviewed at home.	palliative care.	Poor care included futile treatments, lack of joy and hope, ambivalence between hope and reality.	own environment, maintaining dignity, self-determination, professional care.	interesting cultural study, similarities to Canadian research noted.
Mok, Chan, Chan, & Yeung (2003)	To examine the family experience of caring for terminally ill patients with cancer in Hong Kong.	24 bereaved (6 - 12 months) family caregivers of terminally ill Chinese patients .	In-depth, semistructured interviews, grounded theory qualitative method, examining the processes of family members in the context of the Chinese culture, interviews at home or in the clinic.	Interviews, analysis, constant comparative analysis.	Commitment a precondition of caregiving. The work was meaningful. The process of caregiving includes holding onto hope for a miracle. Intense emotional time filled with feelings of hope and hopelessness, guilt, fear, regret.	Caregivers found a change in worldview. Need for effective and culturally sensitive support and affirmation to family members.	Excellent description of choice of methodology, audit trail, purposive sampling, described the process of caregiving, conceptualizing the data.
Oldham & Kristjanson (2004)	To develop a pain education program for family carers of advanced cancer patients.	19 family carers of advanced cancer patients, who reported pain as a symptom. Australia.	Descriptive, qualitative, first part of a 3 part project to develop and test a pain education program.	Semi structured interview, taped and transcribed, content analysis (Patton) Codes, categories, and patterns developed.	Description of pain management problems at home, helpful educational strategies, feelings of suffering and helplessness, and the benefits emerged.	Family members were highly motivated to learn about cancer pain management, wanted to be at home. Video, daily comfort diary, 4 teaching sessions developed as an intervention.	Good description of the research process, sampling, analysis of the data. Results comprised of data, topical survey upon which to build the intervention.
Proot et al. (2003)	Explore the experiences of family caregivers, needs for care, which health services	13 family members caring for terminally ill people at home, all Dutch, 12 were Roman	Qualitative, grounded theory (Strauss and Corbin), constant comparative method.	Open-ended interviews.	Vulnerability a core category, continuous balancing between burden and capacity to cope.	Realistic hope identified as important to reduce fear, hope changes, motivation to maintain an interest in life, life will go on. Support needed	Inter professional research team. Scientific rigor detailed throughout, quotes from the interviews used to

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
	they receive.	Catholic. Netherlands.			Burden, restrictions, fear, lack of support increase vulnerability. Hope, satisfaction, support are factors against fatigue and burnout.	included instrumental, emotional, and information related. Availability of aids, continuity of care.	illustrate key themes in the data. Diagram of vulnerability as being balanced on a scale. Add to our understanding of the experience of caregiving. Practical and useful article.
Rhodes & Shaw (1999)	To examine the care and services received by people in the year before death.	33 interviews, sample was chosen from the death records over one year, Yorkshire, UK.	Qualitative interviews in the home, thematic analysis, exploration of issues around caring, service support.	In-depth interviews with respondents, pre-designed interview guide.	Caring arrangements, employment status, community networks, level of care, intimate care, male carers, social life, access to services, night services, denial and concealment, late diagnosis, pain control, place of death.	Role of the community in providing informal care and the availability of appropriate services to support caregivers. Need for bereavement care programs. Coordination of services, transitions, integration of services.	The report represents a topical survey, data given as received from the participants according to the interview questions. Quotes used, but no analysis or conceptualization of the results. Lack of integration of the results with previous research findings.
Rollison & Carlsson (2002)	Evaluation of next-of-kin's experiences of advanced home care (AHC), information, symptom relief, and caregiving burden.	75 respondents who had a family member cared for at home. Sweden.	Exploratory questionnaire, descriptive study.	Questionnaire.	87% said they would choose AHC again, 88% felt that QOL increased by giving care at home.	Importance of symptom management, support at home, care experience affect their health and ability to function during bereavement, most felt satisfied providing care at home.	Validation of caregiver's needs and expectations for care at home. Limited applicability to area being surveyed as service varies.
Rose (1997)	To examine how carer's cope with	21 families, presentation of 3	Qualitative, case studies, Strauss and	Face to face interviews,	Author recommends that	Carer's have a unique knowledge of the patient,	Lack of scientific rigor, case studies

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
	their relative's pain and medication.	case studies, UK.	Glaser.	telephone conversations, one written statement.	nurses involve carer's in the decision making process.	often not regarded.	given with interpretation by the author, quotes used, lack of themes or conceptual description.
Rose (1998)	To describe, analyze, and interpret the experience of informal carers of terminally ill cancer patients.	55 interactions with 11 families with an adult member with a terminal prognosis, 10 bereaved families, theoretically sampled from urban, rural, UK.	Qualitative, phenomenological hermeneutics, Heidegger.	Unstructured tape-recorded interviews, telephone conversations, one written statement.	One key theme related to perceptions about time and the immense disruption to the structure of their lives. Importance of balancing, managing time, uncertainty.	Time as a theme, with practical suggestions for care of the caregivers. Consideration of the difficulties, the practical tasks in a home environment, emotional tasks, help is significant, appropriate and sensitive support, advice, and information, need for professional support.	Interesting, practical article describing the experience of caregiving. Methodology described but no conceptual description or interpretation of the data results. Concepts found not linked to literature.
Rose, Webb, & Waters (1997)	To gain an understanding of the lived experience of informal carers of terminally ill cancer patients.	21 families, 55 interactions, adult patient with a prognosis of 6 months or less, or who had recently died of cancer. UK.	Qualitative, Heidegger's hermeneutic phenomenology.	Tape-recorded, unstructured interviews, field notes, 10 telephone conversations, a written statement.	Carer's experience conceptualized as work and time. 3 coping strategies were denying, flying in the face of time, normalizing: ordinary time, and togetherness: making the most of time.	Togetherness, a positive view of the situation. Denial a common reaction which may be a negative coping mechanism, less able to make the most of time remaining. One example of a caring team, had a strong faith, found strength in stillness and reflection.	Excellent description of methodology, researcher's roles and processes and theoretical framework. Data conceptualized and discussed in relation to the literature. Scientific rigor addressed and described.
Sherwood, Given, Doorenbos, & Given (2004)	To explore the positive and negative aspects of providing care for someone with	43 bereaved caregivers responded to a mail survey with a questionnaire.	Qualitative mail survey style.	Mail survey, written statements, content analysis of responses.	6 themes identified, the work of caring, informal support, formal support, information,	Practical ways to assist families to cope with role changes, emotional support, respite, need for information. Overall	Thematic survey only, based on written responses, lack of depth to findings. Change of perspective

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
	a brain tumor.	Majority were Caucasian, female respondents. USA.			dealing with symptoms, end of life.	physically and mentally exhausting, but viewed as a privilege and an honor.	during bereavement. Both positive and negative findings emerged.
Stajduhar & Davies (1998)	Exploration of the day-to-day experiences of family caregivers caring for dying loved ones with HIV/AIDS at home.	Theoretical sampling, 7 family caregivers living with the patient, 4 were partners, 2 mothers, 1 a sister. Western Canada.	Qualitative, grounded theory, retrospective interviews within 1 year of death, 4 deaths at home.	Unstructured, in-depth, face-to-face interviews.	Conceptualization model included in the paper, of the experience as an intense, emotional, and powerful experience filled with pride and enrichment, anger, disillusionment. Promising to fulfill wishes, work of caregiving, and context of the work (uncertainty and stigma).	Need for interventions to provide direct and effective support for family caregivers in this situation. Supported caregivers reported finding meaning, learning new things about themselves, and a sense of inner strength, spirituality, and strong belief in life after death. Caregivers who felt unsupported were angry, "stuck in their grief".	Auditability, credibility, fittingness evident, retrospective study, perceptions change. Finding meaning, inner strength, and positive changes cited in contrast to negative outcomes, anger, and isolation.
Stajduhar (2003)	To examine the perspectives of family members involved in the delivery of palliative care at home.	12 dying patients, 13 family members providing care for them, and 47 bereaved caregivers. 28 health care providers and 10 administrators, purposive sampling used. Canada.	Qualitative, ethnographic, examination of the social context of home-based palliative caregiving.	Demographic forms, participant observation field notes, interviews, documents pertaining to family caregiving and home care published in Canada between 1990 and 2000.	Caregiving resulted in life-enriching experiences for many, others felt pressured by the health care system. Life-enriching aspects.	Caregiver choice is complex, home site, stresses to the system to provide consistency in care, education, health care reform type of supports available in each jurisdiction varies, need realistic expectations.	Scientific rigor evident in descriptions of the process of data collections and analysis.
Steele & Fitch	To identify the	20 Caucasian	Nonexperimental,	Jalowiec Coping	Keeping busy,	Family caregivers need	20 caregivers

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
(1996)	use and effectiveness of coping strategies identified by family caregivers of patients with terminal cancer.	family caregivers in 6 home hospice programs in Canada.	descriptive, recruitment of caregivers on admission to a hospice unit. Questionnaires completed at home.	Scale, Caregiver Information Sheet.	thinking positively, learning more about the problem, talking with family and friends identified as effective coping strategies.	encouragement to maintain hope and a positive attitude to continue caregiving. Importance of support for caregivers, explorations of meaning, humor, spiritual care.	identified for the study, although 165 eligible. Sampling bias for coping, small sample size, limited generalizability. Survey to identify key needs and strategies.
Stetz (1987)	To explore the demands made on the spouse caregivers of terminally ill, adult cancer patients.	Purposive sampling of 65 spouses, at home, USA.	Qualitative and quantitative compared.	Semistructured interviews using the Experience of Caregiving Interview Schedule, physical disability of patient measured by the Zubrod scale, care record reviewed.	9 categories of demands: physical care, finances, standing by, constant vigilance, unmet expectations from the health care system, and alterations in relationship with ill spouse.	List of the demands experiences by family caregivers, deterioration of health of the caregiver, teaching and support for coping needed.	Good description of research process, a survey of needs, quantifying according to how many reported the item. No positive aspects of caregiving mentioned or reported. Themes identified not connected to each other.
Strang & Koop (2003)	To examine how caregivers coped while they cared for a dying family member at home. Findings from a larger, qualitative study that focused on the experience of respite and bereavement outcomes associated with home-based	15 family caregivers interviewed twice following the death of their family member. Alberta, Canada.	Qualitative, exploratory, descriptive, research.	Open-ended interview, questions included: How did you manage to cope with caregiving? What did you find helpful/unhelpful?	Coping emerged as a factor needing further analysis; caregivers went to extraordinary efforts to maintain quality and dignity, coping based on the caregivers themselves, the contributions of the dying person, supportive networks. Interfering factors	Faith, believing in a greater being gave the spiritual strength to continue. Attitude of positive acceptance of the death by the care recipient, attitude, spiritual beliefs of the patient. Meaning-based coping helps caregivers shed the unsatisfactory outcome, make new goals, make sense, identify some benefits. Reciprocal interdependent	Scientific rigor explained and detailed. Bereavement phase may have affected the meanings applied. Retrospective analysis of themes emerging from the data. Valuable and useful in practice of nursing. New insights, explain relationship between caregiver and patient.

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
	family caregiving.				were their experiences with the informal and formal systems.	relationship between the caregiver and recipient. Spirituality influences coping.	
Taylor (2003)	To describe the spiritual needs experienced in living with cancer from the perspective of patients with cancer and family caregivers.	28 African American and Euro-American patients with cancer and 7 were family caregivers, USA.	Descriptive, cross-sectional, qualitative.	In-depth, tape-recorded, semistructured interviews, analyzed using data reduction, data display, and verification.	7 categories of spiritual needs: relating to an Ultimate Others, need for positivity, hope, and gratitude, the need to review beliefs, the need to have meaning. Varying levels of awareness of personal spiritual needs. Caregiver needs similar to those of patients.	Comprehensive list of spiritual needs useful to clinicians, although some informants had difficulty understanding the questions, challenging in practice to assess and provide for spiritual needs.	Very good description of previous literature, choice of method supported, sample size determined by saturation, procedures and interview questions described, verification.
Thulesius, Håkansson, Petersson (2003)	To explore what is happening in end-of-life cancer care today, what is the main problem? What are patients and caregivers doing to resolve it?	The researchers conducted 64 formal interviews over 9 years, 26 nurses, 11 physicians, 11 patients, 9 relatives individually and in focus groups. Seminars, workshops, questionnaires from 600 formal caregivers. Sweden.	Qualitative, grounded theory (Glaser). Interviews focus groups, participant observation at hospitals and home care.	Most interviews transcribed, field notes, NUD*IST software.	Imbalance is the main problem, patients suffer the ultimate imbalance, cannot be cured. Balancing is the basic process, weighing, shifting, compensating, and compromising.	"Homeostasis of hope" a regulatory feedback mechanism identified, living in the present, small things are valued, always trying to find a balance between care and cure, symptoms, goals change.	Excellent description of the methodology, framework, and process of research. Extensive data collection resulted in a rigorous interpretive explanation of the grounded theory, fits well with practice. Related to literature on balancing in life.
Willert, Beckwith, Holm, & Beckwith	To examine social support and coping strategies, related	44 spouses assessed within 2 week of patient	Quantitative tests given to spouses, as "part of regular procedures."	Inventory of Socially Supportive Behaviours,	Spouses receiving cognitive information more frequently	Staff should expect increases in anxiety and anger during the initial phases of hospice service,	Ethical issues surrounding the study, difficulty interpreting anger and

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Comments
(1995)	to self-reported depression, anxiety, anger, and physical symptoms in spouses of terminally ill patients recently admitted to a hospice program.	admission, USA.		Coping Strategies Inventory, Beck Depression Inventory, State-Trait Personality Inventory, Wahler Physical Symptoms Inventory.	experienced greater anxiety, coping strategy that was associated with anxiety was wishful thinking.	anxiety better managed when spouses receive directive guidance and when expectations are made clear.	anxiety in having to do a battery of tests at a stressful time.
Yates & Stetz (1999)	To explore how family care-givers develop and respond to an awareness that their relative is dying.	20 recently bereaved (2-4 months) adult family caregivers who responded to a letter of invitation. Australia.	Qualitative, interpretive. Random sample of 20 transcripts out of 105 participants in a larger study, until saturation occurred.	Semi structured interviews transcribed verbatim and content analyzed by data reduction, data display, conclusion and verification. NUD*IST software.	5 major themes emerged, 2 core categories of being uncertain and agonizing, depict the emotional struggles, additional categories of hoping, pretending, and preparing are strategies used by family caregivers to manage these emotional struggles.	An awareness of dying for caregivers is a gradual process, uncertainty and anguish involved, healthcare providers affect the process when families need information. Need to assist family members to maintain hope, transition to palliative care. Hoping a common response enabled them to continue their daily lives, hope for a cure continued, then shifted to relief from suffering.	Process of research, data-gathering, analyzing lends scientific rigor. Effective use of quotes to describe the experience. Conceptual description helpful for practice.

APPENDIX B Ethics Approval University of Saskatchewan

UNIVERSITY OF SASKATCHEWAN
BEHAVIOURAL RESEARCH ETHICS BOARD
http://www.usask.ca/research/ethics.shtml

NAME: Wendy Duggleby (Lorraine Holtslander)   BSC# 03-1370
        College of Nursing
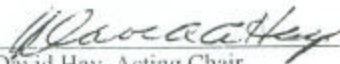
DATE: April 28, 2004

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the Application for Ethics Approval for your study "The Hope Experience of Informal Caregivers of Palliative Home Care Patients" (BSC# 03-1370).

1. Your study was APPROVED January 20, 2004..

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

3. The term of this approval is for 5 years.

4. This approval is valid for one year. A status report form must be submitted annually to the Chair of the Committee in order to extend approval. This certificate will automatically be invalidated if a status report form is not received within one month of the anniversary date. Please   refer   to   the   website   for   further   instructions http://www.usask.ca/research/behavrsc.shtml

I wish you a successful and informative study.

Dr. David Hay, Acting Chair
University of Saskatchewan
Behavioural Research Ethics Board

DH/ck

APPENDIX C Approval Prince Albert Parkland Health Region

PRINCE ALBERT PARKLAND
H E A L T H   R E G I O N

Healthy Living in Healthy Communities

February 2, 2004

Wendy Duggleby
Associate Professor
College of Nursing
107 Wiggins Road
Saskatoon, SK
S7N 5E5

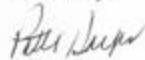Re: Hope Experience of Informal Caregivers of Palliative Home Care Clients

Dear Wendy,

Please consider this letter, on behalf of the Prince Albert Parkland Health Region Ethics Committee, as official approval of the first part of your proposed research study. As indicated in your letter, potential participants will be identified with the assistance of the Home Care Palliative Care Assessor.

Please advise us, in advance, of any significant changes you may implement in your proposed methods or procedures.

Thank-you for your referral. We wish you success with your study.

Sincerely,

Patti Sayer
Acting Secretary
Prince Albert Parkland Health Region
Ethics Committee

Cc: Debbie Skibinsky
Prince Albert Palliative Care Assessor

Pineland Home Care
196 – 9th Street East
Prince Albert, SK S6V 0X5
Phone: (306) 922-2969 · Fax: (306) 763-4472

H:\Documents\Word\Letters\Research approval- Wendy Duggleby.doc (pahd)

APPENDIX D Consent Form

You are invited to partic ipate in a study entitled: **The Hope Experience of Informal Caregivers of Palliative Home Care Patients.** Please read this form carefully and feel free to ask any questions you might have.

Researchers :

Lorraine Holtslander, RN, Master of Nursing Student, Phone: (306) 229-6146

Dr. Wendy Duggleby, RN, Supervisor of Student, College of Nursing, University of Saskatchewan, Saskatoon, SK, Phone: 966-6237 (office) or 220-0296 (cell phone)

Study Purpose:

The purpose of this study is to find out what hope is for you. We need to learn about hope you may be experiencing so that we can better help other caregivers of palliative patients.

Procedures:

If you agree to participate, the researcher, an experienced palliative care nurse, will visit you in your home when it is convenient for you. You will be asked to answer questions about yourself (age etc.) and questions such as age about the person you are caring for. Then you will be asked about hope. Your answers to these questions will be audio taped. The form and questions will take about 45 minutes to an hour. The research assistant will visit you again at a time that is best for you if there are additional questions, or to clarify what you said. Total time for this study may be 2 hours (one hour per visit).

Risks:

Answering the questions may be tiring. You do not have to answer any questions you don't want to. You can stop being in the study any time you want. If you get tired, don't feel well or become upset, you can take a break at any time or end the interview. If you wish the researcher will contact the Palliative Care Coordinator for you.

Benefits:

Taking part in this study will not benefit you directly. Some people have benefited from talking about their situation with a nurse. What you say may help others. The information might be used by nurses and doctors to provide better care for people in similar situations.

Storage of Data:

Your answers to the questions will be stored in a locked drawer at the College of Nursing, University of Saskatchewan for 5 years. Only the research team will be able to look at the information.

Confidentiality:

Your answers will be written down on a form by a researcher. It will not have your name on it. The tape recording will be transcribed, but your name will not be on any of the information. The consent forms will be stored separately from your answers. Your name will not appear in any report. All information from this study will be reported in a group format for conferences and publications so no one can identify you. Although direct quotations will be used they will be presented in such a way as no one can identify you. Your name will not be used and all identifying information (i.e. palliative care services) will be removed from our report.

Right to Withdraw:

You may withdraw from the study for any reason, at any time, without penalty of any sort by telling the researcher. It will not affect the care you or your family member receives.

Questions:

If you have any questions concerning the study, please feel free to ask at any point: you are also free to contact the researchers at the numbers provided above if you have questions at a later time. This study has been approved on ethical grounds by the University of Saskatchewan Behavioral Sciences Research Ethics Board on January 20, 2004. Any questions regarding your rights as a participant may be addressed to that committee through the Office of Research Services (306-966-2084). You can call this number collect. If you would like to find out about the results of the study, please contact the researchers.

Consent to Participate:

I have read and understood the description provided above: I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to participate in the study described above, understanding that I may withdraw this consent at any time. A copy of this consent form has been given to me for my records.

Signature of Participant: _____ Date: _____

Signature of Researcher: _____ Date: _____

APPENDIX E Hope Experience of ICPCP Demographic Form

Date: _____Code No.: _____

A. Participant (Caregiver) Information:

    a. Age_____(yrs)/Gender_____

    b. Years of Education Completed_____

    c. Marital Status: M, D, W, S

    d. Relationship to the Patient_____

    e. Ethnicity: Caucasian_____ First Nations: _____ Asian_____ Other: _____

    f. Religious Preference: _____

    g. Occupation or previous occupation: _____

    h. Current Income: ___less than $10,000 _____$10,000- 19,999___$20,000-$29,999___$30,000 – 39,999__ $40,000- 49,999 ____$50,000 – 59,999 ____$60,000 and more

    i. Medical Conditions: _____

    j. Length of caregiving: _____

    k. Anyone else helping with caregiving? _____

B. Palliative Care Patient Information:

    a. Age: _____(yrs)/Gender: _____

    b. Medical Diagnosis:_____

    c. Date of original diagnosis as palliative care_____

    d. Date of Admission to Palliative Care Program:_____

APPENDIX F Hope Experience of ICPCP Interview Guide

Date: _____

Code No. _____

1. Tell me about hope. (Can you tell me about a situation where you had hope?)

2. What gives you hope?

3. What kind of things change (increase or decrease) your hope?

4. What can others do to help you have hope?

Optional questions:

     What do you hope for in the future?

     What do you hope for now?

     How do you keep hopeful?

     Can you teach someone to have hope?

     What happens if you don't have hope?

APPENDIX G Revised Interview Guide

Revised Interview Guide for Examining Hope in Informal Care Providers of

Palliative Home Care Patients.

Date: _____ Code No. _____

Tell me about hope.

How do you hang on to hope?

How do you build hope?

Optional questions:

      What gives you hope?

      How do you keep hopeful?

      Can you teach someone how to hope? How?

      What takes away your hope?

What happens if you don't have hope?

Is there any thing else you would like to add?

Rev. June 5, 2004

APPENDIX H Example of Coding Process

Transcripts	Incidents	Categories	Concept
<u>Not giving up hope</u>, never, never, never, never, never, no	Not giving up hope		
We just <u>hung on</u> and waited	Hung on		
We all managed to <u>hang on to hope</u>	Hanging on to hope	Hanging on to hope	
There's always some <u>hope there</u>	Finding hope		
Sometimes it's a <u>thread of hope you're hanging on to</u>	Hanging on to thread of hope		Hanging on to hope
It builds your hope what you're <u>hanging on</u> to	Hanging on		
You <u>don't survive</u> without hope	Not surviving		
Most people would <u>give up</u> on this thing	Giving up	Not hanging on to hope	
You <u>found it hard</u>, when she doesn't have good days	Finding it hard		

Source: Author