Searching For New Hope: A Grounded Theory of the Experience of Hope

for Older Women Who Are Bereaved Palliative Caregivers

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In Partial Fulfillment of the Requirements

For the Degree of Doctor of Philosophy in Nursing

University of Saskatchewan

College of Nursing

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By

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Abstract

Purpose/Objectives: To explore the experience and processes of hope for older women who are bereaved palliative caregivers and to develop a substantive theory of their hope experience.

Design/Research Approach: Qualitative, constructivist grounded theory

Setting: Participants' homes in a small Canadian city

Sample/Participants: Thirty interviews with thirteen women, ages 60-79, within the first year of bereavement after providing care to a spouse with terminal cancer, also twelve hope diaries

Methods/Methodologic Approach: Open-ended, in-depth audio-taped interviews, hope diaries, transcribed verbatim and analyzed using constant comparative analysis

Main Research Variables: Participant's descriptions of their experience of hope

Findings: Participants defined hope as a gradual process of regaining inner strength and building self-confidence, to make sense of their totally changed situations. They were learning to stay positive, and move ahead with their lives. Hope was very important to the participants. The participants' main concern was losing hope which they dealt with by searching for new hope through finding balance, finding new perspectives, and finding new meaning and purpose. The theoretical model resembles a spiral and takes place within a social context.

Conclusions: Older women who are bereaved after caregiving for a palliative cancer patient are at risk for losing hope and require support as they search for new hope and move through the complex processes of bereavement.

Implications for Nursing/Interpretation: Health care professionals can provide appropriate and effective care that facilitates positive and healthy bereavement outcomes by monitoring bereaved palliative caregivers at risk for losing hope and supporting them as they search for new hope to find their own way through bereavement.

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Summary

A constructivist grounded theory design was proposed to explore the experience of hope for women who are bereaved palliative caregivers and to develop a substantive theory to explain how these women resolve their concerns relating to hope in their lives. Hope is an important psychosocial resource through difficult life circumstances, yet very little is known about the bereaved palliative caregiver's experience of hope, or how they manage the stressful adjustment from caregiving to bereavement. The research proposal, written in the form of a Canadian Institutes of Health Research (CIHR) Operating Grant application, contains a full review of the scientific literature relating to hope and bereaved palliative caregivers and also the sampling, data collection, and analysis procedures. The specific aims of the study were:

1) To explore the experience and processes of hope for the older, female, bereaved, spousal caregiver of a deceased palliative cancer patient

2) To describe a definition of hope for this population within their social context, and

3) To construct a substantive theory of the hope experience of the older, spousal, female, bereaved, palliative caregiver.

The study was conducted over an eleven month period, from October 2007 to August 2008. During this time there were two changes from the original research proposal. The first was the number of participants and the second was an alternate method of recruitment. Thirteen participants, ages 60 to 79 years, who had received palliative services from the Saskatoon Health Region, were interviewed. The original proposal suggested that 25 participants may be interviewed before theoretical saturation

was reached. Theoretical saturation is defined by Charmaz (2006) as the time in data collection when gathering more data about the categories reveals no new theoretical insights or properties of the emerging grounded theory. Because of the depth and richness of the interviews and diaries and the ability of the researcher to conduct follow-up interviews with most of the participants, theoretical saturation was reached with 13 participants. Also, as the study progressed, a need was identified for finding a second way of recruiting subjects. Further University of Saskatchewan Behavioural Research Ethics Board Approval was obtained to have Eleanor Edwards of the Saskatoon Funeral Home recruit additional participants.

Demographic characteristics of the participants are contained in tables in the manuscripts. Thirty interviews were completed. One participant was interviewed once, and died of complications of heart surgery before a second interview could be arranged. Seven were interviewed twice. Five participants were interviewed three times as they were good informants that provided insights to develop the properties of the concepts and fill theoretical gaps in the evolving theory. Hope diaries were completed by twelve participants and were included in the data analysis. Three of the thirteen participants were having difficulty finding hope in their lives at the time of the interviews and were considered to be contrast cases. For the purposes of this study, a contrast case was defined as a participant whose experience seemed to challenge the emerging theory of hope. This is similar to Charmaz's (2006) reference to the negative case providing a source of variation and density in the emerging theory. The experiences of these women were analyzed further and incorporated into the processes found within the grounded theory.

The consent form, demographic form, interview guide, letter of support, and guide for the participant diaries are contained in the appendices of the research proposal. Appendix A contains the letter of approval from the University of Saskatchewan Behavioural Ethics Board. Appendix B contains the letter of Operational Approval from the Saskatoon Health Region. The findings of the study are presented in two manuscripts, written in the selected journal formats: "Searching for New Hope: A Grounded Theory of the Experience of Hope for Older Women who are Bereaved Palliative Caregivers" and "The Psycho-Social Context of Bereavement for Older Women who were Caregivers for a Spouse with Advanced Cancer." The first manuscript reports the results of the constructivist grounded theory analysis. The participants defined hope as a gradual process of regaining inner strength and building self-confidence, to make sense of their totally changed situations. They were learning to stay positive, and move ahead with their lives. Hope was very important to the participants. Participants described their main concern as losing hope, and the basic social process was searching for new hope. Finding balance, finding new perspectives, and finding new meaning and purpose were the sub-processes of searching for new hope. Implications for practice and research were presented.

The second manuscript describes the psycho-social context of bereavement, data which emerged as meaningful to the participants and directly affecting the processes of hope. The psycho-social context of bereavement includes the intrapersonal aspects of loneliness, pain, exhaustion from caregiving, and physical and emotional concerns. The interpersonal social context includes learning a new a new way of life as a single person, needing the support of others and dealing with difficult relationships. The

community/societal context includes a loss of identity and assuming a new role as a widow, moving, feeling pressured, financial concerns, difficult seasons in the year and relying on the support of the community and the health care system. A diagram illustrating the interactions in the psycho-social context is contained in the paper.

Charmaz (2006) suggests we construct our grounded theories through our past and present involvements and our interactions and interpretations throughout the study. From my experience as a palliative care nurse and my recent study of hope with caregivers of palliative care patients I was aware of the challenges of caregiving and I imagined the overwhelming difficulty of losing a life partner. However, I was surprised by the strength and courage of the participants to find new hope in their situations. During the time of data collection and analysis, it was difficult not to become personally saddened by the hardships experienced by the participants, but I was able to debrief with my co-supervisor, Dr. Wendy Duggleby on many occasions. I learned and applied a constructivist approach to grounded theory, and experienced symbolic interactionism first hand, as I asked the participants to think and talk about hope during their bereavement. Thinking, talking, and writing about hope had an impact on the day to day lives of the participants. Hope was very different now compared to hope during caregiving. The participants had to find new hope as their old hopes were tied to the patient who had died. They were feeling uncertain and hope related strongly to their self-confidence. I continue to be amazed by the uniqueness of each participant's experiences and I feel honored and privileged to have had the opportunity to study their bereavement journey.

Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

PROTECTED WHEN COMPLETED
Application Number

Research Module

Research funding program(s)	CIHR	Rx&D	SME	Salary Support	CIHR	Rx&D	SME
Operating	X	☐	☐	New Investigator	X	☐	☐
Randomized Controlled Trials	☐	☐	☐	Investigator	☐	☐	☐
Research Resource Grant	☐	☐	☐	Senior Investigator	☐	☐	☐
CIHR Team Grant*	☐			Senior Research Fellowship (Phase 2)	☐		
New [X] Renewal ☐				Clinician Scientist (Phase 2)	☐	☐	☐ [X] New ☐ Renewal
Funding Reference Number (FRN):				Research Chair		☐	☐

* A letter of intent to CIHR must precede submission to these programs.

Competition Date:

Proposed Start Date (MM/YYYY) (Salary Programs Only)

Nominated Principal Applicant / Candidate
HOLTSLANDER, Lorraine Fay

Project title:
The Experience of Hope for the Bereaved, Older, Female, Spousal Caregiver of a Palliative Patient.

Primary Location where research will be conducted	Department	Faculty
CCAA University of Saskatchewan	75 - Nursing	275 - College of Nursing

Is this a multi-center study:? Yes ☐ No [X]

Institution which will administer project funds (Institution Paid): CCAA University of Saskatchewan

CERTIFICATION REQUIREMENTS
If this research will involve any of the following, check the box(es). If the grant is awarded, the necessary certification requirements must be met in accordance with policies on ethical conduct of research.

Human subjects [X]   Human stem cells ☐   Animals ☐   Biohazards ☐   Environmental assessment ☐

A requirement for containment ☐   Level 1 ☐ 2 ☐ 3 ☐ 4 ☐

Does this application include a Randomized Controlled Trial? Yes ☐ No [X]

Period of support requested: (For Grants only) 3 Years 0 Months

Language in which proposal is written: English [X] French ☐

Amount Requested from CIHR in First Full Year (For Grants only)

Operating   Equipment   Total Requested

It is agreed that the general conditions governing Grants and Awards, as well as the statement "Meaning of Signatures on Application Forms" as outlined in the Canadian Institutes of Health Research Guides apply to any grant or award made pursuant to this application and are hereby accepted by the applicant(s) and the applicant(s)' employing Institution(s).
The nominating institution recommends this candidate for the salary support award and undertakes (1) to provide adequate accommodation and research facilities, (2) to provide the candidate with an appointment which allows him/her the time to pursue the proposed research (a faculty appointment for those working in a University or affiliated Institution) and freedom to publish the results of the research in the public domain.

Signature of President or Principal of Institution	Signature of Head of Department	Signature of Dean of Faculty or Director of Institution
Print Name :	Print Name :	Print Name :
x	x	x
Date :	Date :	Date :

Research Module, Page 1, Signature Page (12/2005)   Admin use only: 47556

Canada

1. Background: Cancer is a major cause of death, affecting the lives of many Canadians and their families. Most caregivers of terminal cancer patients are older women, entering bereavement after a frequently exhausting and difficult caregiving experience and facing additional secondary losses relating to the loss of a spouse. Caregivers of a deceased palliative cancer patient are at high risk for depression, illness, and even death during bereavement. Hope has been identified as a psychosocial resource for caregivers, a key element in the recovery from bereavement, and a protective factor from the complications of grief. The meaning, experience, and processes of hope have not been previously explored from the perspective of the older, female, spousal palliative caregiver during bereavement.

2. Purpose: The overall purpose of the proposed research is to explore the experience of hope for the older, female, bereaved, spousal caregiver of a deceased palliative cancer patient and to develop a substantive theory to explain how these women resolve their concerns relating to hope in their lives. The specific aims of the research are to: 1) to explore the experience and processes of hope for the older, female, bereaved, spousal caregiver of a deceased palliative cancer patient, 2) to describe a definition of hope for this population within their social context, and 3) to construct a substantive theory of the hope experience of the older, spousal, female, bereaved, palliative caregiver. The resulting theory, grounded in the data, will provide researchers, health care professionals, educators, and decision-makers with a greater understanding of this population's needs from an "insider's" perspective. Analysis of the meaning, concepts, definitions, actions, and processes of hope will provide a grounded theory that explains their experience of hope within a social context.

3. Research Plan: Charmaz's constructivist ground theory methods will be used to gather rich, detailed data through in-depth interviews, participant diaries, and the researcher's field notes and memos. It is expected that approximately 25 women, 60 years of age and older, who have experienced bereavement within the last year, after providing care to a palliative cancer patient, will participate. Purposive and theoretical sampling techniques will be used. A palliative care volunteer will ask participants if they would like to participate in a study about hope, during their first year of bereavement. If they agree, the researcher will contact potential participants, arrange a time to meet, and obtain a formal, written consent prior to the interview. Participants will be interviewed face to face, in their homes using broad, open-ended questions that address their experience of hope during bereavement. They will also be asked to keep a diary of their experience of hope for a one to two week period, either written or spoken into a tape.

4. Data Analysis: The diaries, the researcher's field notes and memos, as well as interview transcripts will be entered into N6 software for coding and analysis. The data will be analyzed using open coding, focused coding, theoretical coding, and constant comparative methods. Confirmation interviews will be conducted with each participant to discuss the emerging theory. Scientific rigor will be sought by the specific criteria of credibility, originality, resonance and usefulness.

5. Significance: Very little is known about the experience or needs of the palliative caregiver facing bereavement, although support for this population is mandated by national and international guidelines for palliative care services. The proposed research would provide insight into the unique perspective of the older, female, spousal

caregiver, during bereavement. Cancer deaths will continue to increase in Canada due to an increasing and aging population. Support for family caregivers after the death of the palliative patient is urgently needed, based on research examining their unique needs.

1. Specific Aims

Cancer will be the world's leading cause of death sometime in the 21st century (1). Many Canadian family caregivers face bereavement each year as a result of cancer deaths. In Canada, there will be approximately 70,400 deaths due to cancer in 2006 (2). Family caregivers play key roles in providing care for terminal cancer patients and have taken on increased responsibility for providing care in the home (3), with consequences affecting physical and mental health in bereavement (4). Older caregivers had a greater risk of bereavement maladjustment (5), especially older, female, spousal caregivers (6).

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 (7, 8). Hope was defined by palliative caregivers as an inner strength and courage to go through a difficult situation (9). In a study of older, grieving spouses, hope was positively correlated with the resolution of grief and hope accounted for 79% of the variance in grief resolution (10). Hope inspiration was a subtle, yet essential process in a grounded theory exploration of hope in bereavement counseling (11). Cutcliffe described the hopelessness found in complicated grief and the re-emergence of hope as an essential aspect of "healthy" grieving. Very little is known about the bereaved caregiver's experience of hope, or how they manage the stressful adjustment from caregiving to bereavement. Exploring the processes of hope from the perspective of the spousal caregiver of a deceased palliative cancer patient is needed in order to provide insight into the caregiver's difficult experience of grief and bereavement, and offer a theory from which interventions, programs, and supports can be based.

The overall purpose of the proposed study is to explore the experience of hope for the older, spousal, female, bereaved caregiver of a deceased palliative cancer patient and to develop a substantive theory to explain how these women resolve their concerns relating to hope in their lives. The specific aims of the study are to: a) to explore the experience and processes of hope for the older, female, bereaved, spousal caregiver of a deceased palliative patient, b) to describe the definitions and processes of hope for this population within their social context, and c) to construct a substantive theory of the hope experience of the older, spousal, female, bereaved, palliative caregiver. The resulting theoretical understanding will provide researchers, health care professionals, educators, and decision-makers with a greater understanding of hope in this population, supporting caregivers through their time of grief and bereavement and promoting a healthy adaptation to a challenging life event.

2. Background

Exploratory, descriptive research is needed to examine the experience of hope in bereavement as: a) there are many unresolved concerns during grief for palliative caregivers, especially for the older, spousal, female, bereaved caregiver, b) hope is an important variable in the processes of grief and bereavement, and c) very little is known about the experience of hope for the palliative caregiver after the death of the palliative cancer patient.

Research with bereaved palliative caregivers described their many unresolved concerns, including intense grief (12), acute distress (13), and feeling a lack of support (12-16). In a grounded theory study of six older female, bereaved caregivers, the participants described feelings of exhaustion from caregiving, acute distress, and sleep

disturbance (13). A sample of 124 bereaved caregivers was interviewed within three months of the death of a cancer patient; caregivers were at higher than normal risk for depression (17). Similarly, in a study of 174 primary caregivers of cancer patients, between 9% and 24% experienced major depression at 6 months post-bereavement (18). Canadian researchers interviewed a convenience sample of 151 caregivers by telephone and found increasing age, the loss of a spouse, and difficulties in caregiving predicted significant declines in mental and physical health during bereavement (4, 19).

Hope was measured in a correlational study of hope, coping styles, and grief in a random sample of 75 elderly persons, widowed 12 – 18 months (10). Hope correlated with grief resolution as an important variable in the recovery from the loss of a spouse. In a grounded theory study of the experience of bereavement, open-ended telephone interviews were conducted with 34 participants, mostly younger women, from a wide range of experiences relating to the death of a loved one (20). The participants described hope as a source of consolation in grief. Holding on to hope was a constant theme and individuals emerged from feeling hopeless towards renewed hope and meaning. Embracing hope allowed survivors to find new meaning and purpose in spite of the death. A review of the scientific literature of hope, including: a) current theories of hope, b) hope and palliative caregivers and c) hope during bereavement, provides a framework for the proposed research.

a). Current theories of hope: Hope was defined by Farran, Herth, and Popovich as a basic requirement of the human condition; a way of feeling, a way of thinking, a way of behaving, and a way of relating to oneself and one's world. It was an experiential, spiritual, rational thought, and a relational process (21). Other hope theories, including Cutcliffe (11), Snyder (22), Dufault and Martocchio (23), from the fields of nursing and psychology, provide an overview of the current perspectives of hope found in the literature. Each theory provides insight into the processes of hope, but is derived from research using differing methodologies, philosophies, and participant samples.

Cutcliffe, a mental health nurse researcher (11), defined hope, based on an overview of current literature, as multi-dimensional, dynamic, empowering, central to life, related to external help, related to caring, orientated towards the future, and highly personalized. He recognized the need for a theory of hope in bereavement counseling and conducted a qualitative grounded theory inquiry with 12 participants who were bereavement counselors and ex-clients of bereavement counselors. The core variable in the process of bereavement counseling was the implicit projection of hope and hopefulness. Hope occurred as a subtle process in the relationship between counselor and client. A transplantation or direct transfer of hope occurred through the caring relationship. A re-emergence of hope was connected to a completed bereavement process. Cutcliffe researched hope from the perspective of the bereavement counselor and did not explore the meaning and inner processes of hope for persons actively going through grief and bereavement.

Snyder, a clinical psychologist, developed a theory of hope by measuring hope quantitatively, with various samples of adults, adolescents, children, college students, athletes and coaches, and adults in combat (22, 24, 25). Snyder defined hope as "the perceived capability to derive pathways to desired goals, and motivate oneself via agency thinking to use those pathways" (22). Hope involved feed-forward and feedback

mechanisms and an interrelated system of goal-directed thinking that responds to emotional feedback. Hope is a thinking process in which a person clearly conceptualizes goals, but also believes that pathways to these goals can be produced, initiated and sustained.

Dufault and Martocchio (23) developed a widely cited theory of hope, offering a broad picture of hope, which included generalized hope as an abstract phenomenon and particularized hope as directed towards a specific hope object. Hope was defined as a "multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good, which to the hoping person is realistically possible and personally significant" (p. 380). Their theory was based on interviews, participant observation, and clinical data with a sample of 35 elderly cancer patients, and confirmed with another sample of 47 terminally ill persons. Loss was described as an activation of the hoping process or as a test of hope, suggesting the importance of hope in the context of bereavement.

Farran, Herth, and Popovich (21) described hope based on a literature review of qualitative and quantitative research studies about hope, their own research, and their knowledge from practice. They declined to put forth a single theory of hope, preferring individual application in practice situations. The spiritual dimension of hope is not explicit in the theories of Snyder or Cutcliffe, although it is included in other theories of hope (9, 21). For example, in a grounded theory study of hope with participants who were actively caregiving for a palliative family member, hope was not goal-directed, but rather an inner strength and courage to go through a difficult situation (9). Theories of hope point to the importance of understanding the actions, processes, and conditions for hope, but do not explain hope within a social context, specific to a population experiencing grief. The bereaved palliative caregiver's definition, meanings, and processes of hope would provide increased applicability, practicality, and usefulness in meeting the needs of this population during grief and bereavement.

b.) Hope and palliative caregivers. Hope was defined in studies of the hope experience of participants providing care to a palliative patient, as an effective psychosocial resource to cope with a difficult caregiving experience (7-9, 26). Hope and constructive coping were positively correlated in a convenience sample of 61 family members of a palliative cancer patient; hope provided an incentive for constructive coping with anticipated loss (26). Herth conducted a longitudinal, mixed methods study with 25 family caregivers who defined hope as a dynamic inner power that enabled transcendence of the present and fostered a positive awareness of being. The Herth Hope Index was used to measure hope scores, which rose and remained stable through the experience. This was inconsistent with the qualitative results, which described hope as fluctuating, based on the inevitable difficult aspects of the palliative caregiving experience. It is difficult to measure hope within a complex, ever-changing experience.

In a mixed methods study with a sample of 51 family caregivers of palliative cancer patients (7), hope stemmed from faith, connections with God and with others. Barriers to hope were fatigue and the patients' symptoms not being controlled. Similarly, measurements of hope, hopelessness, and fatigue, in a convenience sample of 85 Swedish patients and family members, indicated that fatigued family members had lower hope scores than the patient, indicative of the difficulties faced by caregivers in

maintaining hope (27). Increasing age of the family member was correlated with a lower hope score and increased hopelessness.

In a grounded theory study (9), a sample of ten family caregivers, living with and providing care for a palliative patient, defined hope as their inner strength. Hope was constantly fluctuating, based on what was happening with the dying patient. The focus of their hope was to do a good job as caregivers, to not give up, and for the patient to not suffer too much. "Eroding hope" was the main concern relating to hope during caregiving. Eroding hope was a result of bad days for the patient, negative messages, and experiences with the health care system. The participants dealt with eroding hope by using the basic social process of "hanging on to hope." Hanging on to hope had 4 sub-processes: a) doing what you have to do, b) living in the moment, c) staying positive, and d) writing your own story. Since the caregivers' hope was focused on the patient and their own caregiving, bereavement would present new and different challenges to hope, due to the loss of the palliative patient, the end of caregiving, and the major role adjustments involved, especially for older, spousal caregivers (4).

c). Hope during bereavement. The only study found to focus on the experience of hope for people experiencing bereavement, was a correlational study of hope, coping, concurrent losses, and setting to grief resolution for the elderly widow(er) (10). A stratified, random sample of 75 elderly persons, widowed 12-18 months after the death of a spouse in either hospital, hospice, or home, completed questionnaires on hope, grief, and coping, by mailed surveys. The level of hope correlated positively to grief resolution and the use of self-reliant, confrontive coping styles. No difference between genders was found in the level of hope, coping style, or grief resolution. Overall, hope accounted for 79% of the variance in grief resolution. The findings validate the essential aspect of hope in grief; however, insight is needed into the inner processes and meaning of hope for the caregiver of a palliative patient during bereavement.

d). Key conclusions on which to frame the proposed research: The science of hope provides a strong rationale for the importance of hope during grief and bereavement. Specific key factors in the bereavement experience and the literature of hope emerge to provide a framework for the purposive sampling that will be employed in the proposed research, including i) age of the caregiver, ii) length of caregiving, and iii) the caregiver's support systems.

i) Age correlated with decreasing levels of hope and increasing levels of hopelessness for the family caregiver of a palliative patient (27). This is different than a mixed method study of hope by Borneman et al (28) where hope increased with age of the caregiver, during caregiving. However, in research exploring the bereavement experience of caregivers of a palliative cancer patient, increasing age predicted more difficulties with physical and mental health in bereavement (5, 6, 19).

ii) Length of caregiving, and related fatigue, predicted significant declines in mental and physical functioning in bereavement (4, 29). If caregiving resulted in declining health and significant interruption of activities a significant decline in physical and mental health status was predicted to occur in bereavement (4, 5, 19).

iii) Support systems. Relationships and adequate support systems have been cited as significant to maintaining hope in previous research with palliative caregivers (8, 28).Social support predicted less depression in bereavement (30, 31).

Hope, although an important variable in grief (10), has not been investigated from an "insider's" perspective. The background literature researching bereaved palliative caregivers provides a framework to pursue an in-depth investigation of the processes and meaning of hope. Older women, who have provided care, and may not have adequate support systems, are at particular risk for bereavement difficulties, will be the focus of the proposed research.

3. Preliminary Work

Through more than 18 years as a palliative home care nurse, the researcher has witnessed the stress and also the rewards experienced by the family caregiver of a dying family member. Lingering questions and concerns about the situation of the family caregiver after the death of the palliative patient prompted the proposed research into the caregiver's experience of hope through bereavement. Through the difficulties of providing care, and considering the physical, social, financial, and emotional strains of caregiving, an insufficient amount of assessment, intervention, or support is offered or made available to the bereaved caregiver. The bereaved palliative caregiver, no longer a vital resource to the health care system, is left to struggle through grief with a limited amount of effective support. Very little research has been conducted to examine the needs of this population. In the context of primary health care, much could be done to promote a healthy and safe transition through bereavement, by offering accessible supports that recognize the importance of hope, based on research designed to discover their unique perspective.

The proposed research will build on the researcher's Master's thesis, a qualitative study of hope for the family caregiver of a palliative patient, which applied Glaser's (32) grounded theory methods. Building on the background literature, the author's previous research, and applying Charmaz's (33) constructivist grounded theory methodology; this study will search for the meaning, actions, processes of hope for the palliative caregiver during bereavement.

4. Study Design and Method

a). Research Design: In order to accomplish the specific aims of the study, constructivist grounded theory methods, as described by Charmaz (33, 34) will be used. A consistent approach, applied throughout the research process, based on the original sources for design and analysis, is recommended for achieving quality in qualitative research (35). A conceptual analysis or interpretive explanation of the data, will conceptualize the findings and increase the applicability of the results (36). Grounded theory is especially useful to explore and build theory for situations in which a change process or transition is expected, with a number of stages (37). In grounded theory the researcher asks "What is going on here?" as a starting point when little is known or understood about the complex situation being examined (37). Grounded theory has its origins in symbolic interactionism, a theoretical perspective that assumes society, reality, and self are constructed through interaction, relying on language and communication. Interaction is dynamic, interpretive, and addresses how people create, enact, and change meanings and actions (33). When humans interact they find meaning in a situation, which affects their behavior, reality is negotiated between people, changing and evolving constantly (38). Glaser and Strauss (39) were the originators of

grounded theory methods, applying a positivistic, empirical approach to building theory. Charmaz (33) has provided a way to use grounded theory, within twenty-first century methodological assumptions of constructivism. A constructivist orientation, as part of an interpretive tradition, seeks to conceptualize the studied phenomenon, articulate a theory in terms of scope, depth, power and relevance, while acknowledging subjectivity and the need for dialogue, understanding, and meaning (33). As further described by Charmaz, a grounded theory is situated in a social context and situation, open and alert to the conditions under which an experience is subject to differences in power, communication, and opportunity that maintain and perpetuate differences and distinctions. Because of the limited research in the complex and contextually based phenomenon of hope for the older, female, spousal, bereaved palliative caregiver, and the process nature of grief (20), constructivist grounded theory is well suited to the aims of the study.

The loss of a spouse in older adulthood presents the caregiver with, in many cases, tremendous grief as well as secondary losses in lifestyle, independence, and finances (40). The situation, experiences, and processes used to adapt to the loss will be different for older versus younger spouses and is best examined separately in order to uncover the specific consequences of their loss (41). The majority of caregivers of palliative patients in Canada are older women (3), facing more difficulties in bereavement than men (40), multiple losses, and greater distress and grief than other populations of caregivers (6). Older, female, spousal caregivers of a palliative cancer patient have unique needs and experience immense difficulties in their journey through bereavement (4, 6, 12, 19).

Based on the background literature and previous research, hope will be studied as a sensitizing concept (33). Hope was an important aspect of the grieving process (20). The concept of hope will provide the framework to guide the study towards discovering the social processes older, female, bereaved palliative caregivers use to adapt and respond to one of life's major challenges.

b). Setting for the Research: The research will be conducted in the homes of older, female, spousal caregivers of a deceased cancer patient. Participants will be living within the Saskatoon Health Region and have received care from Regional Palliative Care Services. The Saskatoon Health Region serves a population of almost 300,000 people. From April, 2004 to March, 2005 there were 1317 admissions to palliative care services in the city of Saskatoon. Approximately 85% of these were cancer patients (personal communication, Meredith Wild, Manager, Palliative Care Services for the Saskatoon Health Region, March 23, 2006). The Saskatoon Health Region offers bereavement services to families over the first year, consisting of follow-up through phone calls made by volunteers, mailings offering information and contact numbers, support groups, memorial services throughout the year, and referrals to social workers as needed or requested.

c). Sample: The sample for the study will be older, female, spousal caregivers of a deceased palliative cancer patient. Inclusion criteria for the sample will be: women ages 60 and over, who previously resided with and provided care for a spouse with terminal cancer who died within the last year, English speaking, and freely consenting to be a participant in a research project about hope in bereavement. Exclusion criteria will be: those cognitively impaired, non-autonomous, or not able to give a free and informed

consent, as determined by the Volunteer Coordinator, who will make initial contact with the participants.

Meredith Wild, Manager of Palliative Services for the Saskatoon Health Region, has agreed to make arrangements for the Saskatoon Health Region: Palliative Care Services Volunteer Coordinator, to provide the initial contact with bereaved caregivers by phone. (A letter of support from Meredith Wild is found in Appendix D.) The researcher will meet with the Volunteer Coordinator to explain the purpose of the study and the sample selection criteria. Bereaved caregivers, who meet the inclusion criteria, will be identified from a list of all family caregivers who have been part of the palliative care program over the last year. The Volunteer Coordinator will contact potential participants, who meet the selection criteria, to describe the study and ask if a researcher could contact them. If they agree to participate, the Volunteer Coordinator will contact the researcher and provide the name and phone number of the potential participant to the researcher. The researcher will contact with the participants to arrange an interview, explain the study, and obtain written consent (Appendix A).

The researcher, a palliative home care nurse with the Saskatoon Health Region, has excellent support from and a good working relationship with Meredith Wild, the Manager of Palliative Services, and will continue to meet frequently with her and the Volunteer Coordinator to answer any questions or concerns as the study progresses.

The size of the sample will be determined by saturation towards theoretical completeness, until no new properties of the categories or theoretical insights are being gained (33). Charmaz describes the need for large sample sizes in a study examining a complex human phenomenon in order to reach and prove theoretical saturation:

> A small study with modest claims might allow proclaiming saturation early. Researchers who make hefty claims should be circumspect about the thoroughness of their data and the rigor of their analyses. A study of 25 interviews may suffice for certain small projects but invites skepticism when the author's claims are about, say, human nature or contradict established research. ((33)p. 114).

In order to seek and establish credibility, thoroughness, and rigor (33) in the meaning and actions of hope during bereavement, it is anticipated that approximately 50 interviews will be conducted with 25 caregivers. If possible, second and third interviews will be conducted with each participant, to explore in more detail the concepts that emerged from previous interviews and their journals, to confirm the emerging theory of the processes of hope in bereavement.

Older, female, bereaved palliative caregivers will be purposively and theoretically sampled to obtain a wide range of experiences and situations relating to their bereavement. Purposive sampling will be focused on achieving diversity in the sample, seeking a mixture of ages equal to and older than 60 years, different lengths of caregiving time, and a variety of social support situations. As the study progresses, other factors will be determined to guide purposive and theoretical sampling. Theoretical sampling strategies will be used to narrow the focus of the data collection to the emerging categories, in order to develop and refine them, elaborate their meanings, discover variation, and define the gaps to find a full range of the experience of hope during bereavement. Theoretical sampling will become more focused on the social processes, concepts, and categories, until saturation of the categories and their properties

is achieved. Participants are sought who best represent or have knowledge of the research topic, from a range of experiences and backgrounds, for efficiency, and to gain saturation and replication. Follow-up interviews will be conducted on the major ideas, to elaborate the categories, their relevance, and to fully saturate the properties of the emerging grounded theory (33).

   d). Data Collection Tools: As recommended by Charmaz (33), rich and sufficient data consists of collecting background data about the persons, processes, and settings, including a full range of contexts, and detailed descriptions of the participants' views and actions. Rich data reveals what lies beneath the surface, incorporates multiple views, and comparisons across and between the data. Charmaz recommends two or more data-gathering approaches for a large project such as a thesis. Therefore, data collection will consist of a demographic form, face to face open-ended audio-taped interviews conducted by the researcher, written or audio-taped diaries or journals from the participants, and the researcher's field notes and memos.

   Demographic Form: Rich and sufficient data include enough background data about persons, processes, and settings in order to portray the full range of contexts of the study (33). The demographic form, found in Appendix B, includes information about age, length of caregiving, social supports, socioeconomic factors, living arrangements, physical health, and use of the health care system. The demographic form will make available useful background data to set the emerging grounded theory in a social context, fully describe the research sample, and provide a guide for purposive sampling.

   Interviews: The interviews will be conducted in the homes of the participants, or in any other comfortable, quiet location based on a participant's preference. After consent is obtained and the demographic form is completed, face-to-face interviews will be conducted with the participant, using broad, unstructured questions adapted from the researcher's previous study (9), and incorporating Charmaz's suggestions for interview questions (33) (See Appendix C for the proposed interview guide). The questions are broad and open-ended, formulated to give the participants an opportunity to provide the researcher with their own thoughts about hope, and not to just answer the researcher's questions. After each interview, a time will be provided for debriefing with the participant.

   Interview transcripts will be analyzed following each interview and the interview questions may be changed to become more focused on the emerging theory. The interviewer will listen carefully to the participants' genuine concerns, perspectives, and meanings, in order to determine what is important for these caregivers in their own context. Interview questions may change based on the emerging categories, developing, elaborating, and refining their properties, meanings, the relationships or links between the categories, and the identifying variation in a process.

   Journals or Diaries: A written journal can encourage frank disclosures that may not come out in an interview situation (33). Written accounts, situated in a context, provide insight into the meanings, perspectives, practices, and events not easily obtained in interviews. Diaries have been used in previous research with older adults to successfully obtain rich data, written or taped for a short time each day, over a recommended time frame of one to two weeks (42). Recording or writing in a journal about hope will encourage deeper insights into the daily struggles of grief and hope for the participants. Collecting participants' written personal accounts provides a way to

gather rich data, to compare data, to explore ideas about codes, and to direct future data-gathering. Following-up on ideas from the journals in an interview will provide rich, deep data and strengthen the study (33).

Participants will be asked to begin a journal after the first interview. The researcher will provide a notebook and pen, or a tape-recorder and audiotapes, and written instructions. They will be asked to take five minutes at the beginning or end of every day, to think about and describe what hope meant to them that day, and what actions, activities, or specific supports hindered or helped their hope. (See Appendix E for the written instructions being given to each participant.) After two weeks, the journals will be collected for photocopying and/or transcribing, and subsequently returned to the participant to keep.

Field Notes Field notes will be recorded of the setting of the interview, important nonverbal communication, and general observations of sights, sounds, and feelings about what is going in. Field notes will be transcribed and entered into N6 software.

Memos: Memos form the core of grounded theory (33), as an important step between data collection and writing drafts. Memoing includes the interviewers' thoughts and feelings about the interview, ideas about the emerging theory, and the research process including questions, gaps, and the analytic progress of the research, providing a record of the research and the analytic process (33). Ongoing memo writing forces the researcher to analyze ideas as they arise, and increase the abstraction of the data. The researcher examines her own ideas, in comparison to those emerging from the data, to stay grounded in what is going on in the participant's lives, an open, honest account of values, codes, and categories. Memo-writing leads to theoretical sampling. Relevant literature will be integrated throughout the research process in order to fill in the missing pieces of the emerging theory.

e). Step by Step Data Collection Procedures and Time-Line for the Study: After ethical approval from the University of Saskatchewan and the Saskatoon Health Region has been obtained (during August – September, 2006), the researcher will meet with the Volunteer Coordinator and Manager of Palliative Care Services, to explain the purpose of the study and the sample selection criteria. Written material describing the study will be provided. The Volunteer Coordinator will contact potential subjects, who meet the selection criteria, and ask them if a researcher could contact them about the study. If they agree to participate, the Volunteer Coordinator will contact the researcher and provide the name and phone number of the potential participant. Ongoing contact will be maintained to answer any questions or concerns.

The researcher will contact the participant and arrange a time and place for an initial interview. At this interview, a written informed consent will be obtained (see Appendix A) and a demographic form will be completed (Appendix B). The interview will be guided by the questions found in Appendix C. After the interview, the participant will be asked to keep a journal or diary for a time period of 1 to 2 weeks. The diaries will be collected after 2 weeks, photocopied and transcribed, and returned to the participant.

Data will be analyzed during data collection, which is expected to occur over a period of six to nine months (September, 2006 to May, 2007). The interview and diary transcripts will be analyzed before a second interview commences to confirm the collected data, emerging categories, properties, meanings, and theoretical insights. At

the second visit, additional interview questions will be used, based on the first interview and the written journals, the developing social process, and if possible, the emerging theory, for confirmation by the participant and to obtain depth and insight into their experience of hope. If possible, a third interview will be conducted to gain deeper insights and to confirm the emerging grounded theory.

Writing of results will occur in June, July, and August, 2007. The final dissertation will be ready for defense by September, 2007.

f). Data Analysis and Interpretation: All interviews, participant journals, and field notes will be audio-taped, transcribed verbatim, and checked for accuracy. Interview transcripts, field notes and memos, and the written or taped journals will be entered into N6 software in preparation for data analysis.

The data analysis of the interviews, journals, and field notes will consist of initial, focused, and theoretical coding. The participants' journals will also be analyzed using Charmaz's constructivist grounded theory methods (33), paying attention to the context they were written in, as well as the content, including the embedded meanings, the categories discerned, changes over time, and comparing the texts with each other. The journals will be compared to the interview transcripts and memos, to fully integrate and saturate the meaning, concepts, and categories of the emerging theory of hope.

Initial coding will involve examining the data line by line, searching for categories, concepts, and patterns of behavior, in order to identify, label, categorize, summarize, and account for each part of the data. Codes will use the participants' language, or *in vivo* coding, to provide an important check on the significance of the codes to the participants' specific meanings and experiences. The initial codes will use a phrase to name each word, line, or section of the data, to find the actions, and to capture and condense meaning. Initial coding will involve taking all of the data, separating it into categories, and searching for and identifying processes, meanings, actions, change, and consequences. These initial codes, the gaps emerging in the data, and the need to develop the properties of the categories will provide leads that will be pursued in ongoing data collection. The researcher will remain open to emerging ideas, stay close to the data, and construct codes that are simple, precise, active, and analytic (33).

Focused coding is the second major phase of data analysis, identifying the most significant or frequent initial codes in order to sort, synthesize, integrate, and organize the data (33). Codes will be developed into categories and incidents. The initial codes will be examined in terms of their impact and significance for the participants. Data will be compared to data, categories to categories, and incident to incident, to develop the properties of the focused code and categorize the data incisively and completely. Constant comparison will be used to move across the data, comparing data to the codes, categories, and incidents, to develop and refine the focused codes.

Theoretical coding will involve analyzing the focused codes and specifying the relationships between the categories and concepts. The focused codes will be integrated and organized into a logical, coherent emerging theory of the bereaved palliative caregiver's experience of hope. The data will be theoretically sampled, conceptualized into categories, sorted into theoretical codes, and integrated into a theory of the processes and meaning of hope for the palliative caregiver during bereavement inclusive of the social context. The resulting constructivist, grounded theory, confirmed with

selected participants at confirmation interviews, will be a creative interpretation that explains, organizes, and presents the data (33).

g). Scientific Rigor: Charmaz (33) describes the specific criteria of credibility, originality, resonance, and usefulness to guide and evaluate constructivist grounded theory that will have fit, work, relevance, and modifiability. Credibility and quality in research from a constructivist paradigm recognizes subjectivity as an essential aspect, trustworthiness of the researcher and the findings, triangulating the results, paying attention to reflexivity, praxis, and particularity, seeking enhanced and deeper understandings, and contributing to an ongoing dialogue (35). **Credibility** will be enhanced by gathering rich data from multiple sources, and seeking depth and variation in the data. Interviews, journals, field notes, and memos, will be transcribed verbatim. Staying close to the data by initial, line by line, and *in vivo* coding, will facilitate the construction of a grounded theory that reflects the participants' experience of hope. Keeping raw data, field notes, and memos, will provide an audit trail of the various steps, from the raw data to analysis and interpretation. The results of each interview, and the emerging theory, will be confirmed with the participants at a second and possibly third interview. The grounded theory should make sense to the participants, offering deeper insights, interpretations, and a useful contribution to their lives (33). **Originality:** Hope research, with the palliative caregiver during bereavement has not been previously reported and will provide fresh insights by a conceptual rendering of the data, with social and theoretical significance that challenges and extends current ideas, concepts, and practices. **Resonance** will be sought by fully saturating the categories, revealing the meaning of an experience, the contextual links, and giving deeper insight into the lives of the participants. Grounding theoretical observations in the data and cross-coding and categorizing data will ensure fittingness. **Usefulness** speaks to the practicality of the theory, as a spark for further research, contribution to knowledge, and to making a better world. Close attention to the meanings and actions of the participants and seeking confirmation of the developing theory will advance fit, work, relevance, and modifiability.

h). Protection of Human Subjects:

The proposed research will be submitted for ethical approval from the University of Saskatchewan Behavioral Research Ethics Board and the Saskatoon Health Region. The guiding ethical principles of respect for human dignity, respect for free and informed consent, respect for vulnerable persons, respect for privacy and confidentiality, respect for justice and inclusiveness, balancing harms and benefits, minimizing harms, and maximizing benefits must be in place in the research design (43) and be a dynamic process throughout the research (44).

Parkes (45) has identified people going through bereavement as potentially vulnerable due to the presence of strong emotions which may impair their judgment, their ability to concentrate, and their ability to appraise risks. This potential risk will be addressed in several ways. First, the researcher will contact the palliative care coordinator, social worker, or family physician if assistance is needed by the participant before, during, or after the interview. A written list of community resources for grief will be provided to participants. Potential risks to the participants may include an emotional response when discussing sensitive issues and fatigue resulting from the interview. Interviews will be stopped if a participant wishes, and if necessary, assistance

will be obtained to minimize the risks. The interviews will be kept to fewer than 60 minutes to prevent fatigue. Interviews will be conducted by the researcher, a registered nurse, sensitive to their needs, and comfortable with emotional issues that may arise. The research will take place under the expert guidance of the researcher's doctoral committee, familiar with grief and bereavement issues. Previous research indicated that most participants found an interview about their experience of bereavement to be helpful to them, and not distressing; expressions of distress were found to be therapeutic and of benefit to them in the interview context (46).

Participants will be asked if they would like to be involved in the study by an impartial contact person, thus an informal consent will be obtained prior to being contacted by the researcher. Written, informed consent will be obtained from each participant before the first interview. They will be informed of the research study purposes, any benefits or risks, and that they can withdraw from the study at any time without penalty. All data will remain confidential; consent forms will be obtained and stored separately from the data. Only code numbers will be used on the data and reporting will be in a group format. The data will be locked in a file that only the supervisor and researcher will access and will be kept for at least five years, according to the University of Saskatchewan policy.

i). Limitations of the Study: The limitations of the study include the sample characteristics, the context of the study, and the methodology. The sample will be from a mostly urban area, with access to a comprehensive palliative care program which considers the needs of the bereaved. The sample will be English speaking and from religious and ethnic groups representative of a mostly urban population, within a Western Canadian context, which may influence the results of the study. The sample will be limited to women available and willing to participate in the study; those in the greatest distress may not agree to participate. Future research needs to be conducted with other populations such as male, spousal caregivers, younger caregivers, and rural and remote populations of caregivers. Other limitations include the possibility of not identifying a major category, not adequately describing the properties of each category, or failing to obtain a deep, and rich insight into the hope experience of the older, spousal, bereaved palliative caregiver. The study may be descriptive rather than interpretive and lack insight or not reach theoretical saturation. The grounded theory will be a reflection of the participants' personal experiences; the readers will 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. The Research Team

The research will be conducted under the guidance of the researcher's doctoral committee, experts in the areas of grief, bereavement, hope, and palliative care, and the processes of conducting research. The researcher is co-supervised by Dr. Wendy Duggleby and Dr. Lesley Degner. Committee members include Dr. Anne Leis, Dr. Michael MacLean, and Dr. Karen Wright. Dr. Duggleby is currently a principle investigator on several externally funded grants (SHRF and CIHR) focusing on hope in palliative care patients and their informal and formal caregivers. Dr. Lesley Degner is a CIHR/ CHSRF chair in development of evidence-based nursing practice in cancer care, palliative care and cancer prevention. Dr. Anne Leis, from the Department of Community Health and Epidemiology at the University of Saskatchewan, is a researcher in the areas of quality of life, psychosocial

oncology, palliative care, and spiritual needs. Dr. Michael MacLean, Dean of the Faculty of Social Work at the University of Regina, conducts research in end-of-life care for seniors and the promotion of positive aging for the individual and for society. Dr. Karen Wright is an Associate Professor, College of Nursing, University of Saskatchewan, whose professional practice and research focus is on loss, grief, and bereavement; family coping; quality of life, and women's issues. The strong support from the researcher's committee members will ensure the research is of good quality by lending their expertise throughout the process of the research. The researcher, who will be conducting the interviews, is a registered nurse, comfortable with emotional issues that may arise and familiar with available supports in the health region and the community.

6. Knowledge Transfer

The overall goal of the research is to improve the health of the palliative caregiver during bereavement, advocating for more effective, efficient, and equitable health care services by giving a voice to the needs, perspectives, and difficulties of this unique population, and their need for hope. Results of this study will be published in peer reviewed journals, presented to a wide variety of audiences, both professional and community-based, and posted on a website. Workshops, local, national, and international conferences, and public forums will be sought in which to present the results, in order to generate discussion and raise awareness of the needs of the bereaved palliative caregiver.

7. Significance

The grounded theory approach will identify further specific research questions and challenges, sensitizing concepts to pursue, build a theory base, and advance knowledge for practice, education, and ongoing research. Support for family caregivers is urgently needed as deaths from cancer will continue to rise in Canada. Research examining the experience of hope, from the perspective of the palliative caregiver during bereavement is innovative and provides opportunities to develop theory-based interventions, programs of support, and policies of care to promote healthy and safe outcomes through the difficult transition after caregiving into bereavement. Bereavement care is a necessary, yet often neglected aspect of the trajectory of palliative care services. As described by the World Health Organization (47), the mandate of palliative care services extends into the bereavement phase of a life-threatening illness, providing support to survivors as they make a difficult transition in their lives. Most Canadian caregivers of terminally ill cancer patients are older women, facing unique challenges that need further investigation in order to provide adequate support to this population. Understanding the experience of bereavement and providing compassionate support has been identified as the most important factor in all bereavement interventions (48). Hope has not been researched from the perspective of the palliative caregiver during bereavement in previous studies. Theory-based interventions can be developed and tested based on the findings of this grounded theory exploration. Evidence from research is needed to plan services, supports, policies, and program evaluations from which the health care system has the opportunity to facilitate positive outcomes for caregivers going through bereavement. Future research needs to be conducted with different methodologies and samples such as the populations of male, spousal

caregivers, younger caregivers, different cultural groups, and rural and remote populations of caregivers.

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Appendix A Consent Form

You are invited to participate in a study entitled: **The Hope Experience of Older, Female, Spousal, Bereaved Caregivers of Palliative Patients.** Please read this form carefully and feel free to ask any questions you might have.

Researchers:

> **Lorraine Holtslander**, RN, MN, PhD (c), College of Nursing, University of Saskatchewan, Phone: (306) 229-6146
>
> **Dr. Wendy Duggleby**, RN, DSN, AOCN, Co-Supervisor of Student, College of Nursing, University of Saskatchewan, Saskatoon, SK, Phone: 966-6237 (office) or 220-0296 (cell phone)
>
> **Dr. Lesley Degner**, RN, PhD, Co-Supervisor, College of Nursing, University of Manitoba, Winnipeg, Manitoba, Tel: (204) 474-6767

Purpose and Procedures:

The purpose of this study is to find out what hope means for you during grief and bereavement. Nurses need to learn about hope during bereavement so that we can better help other persons in similar situations.

> If you agree to participate, myself, the researcher and 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 were caring for. Then you will be asked about hope. Your answers to these questions will be audio taped with your permission. The form and questions will take about 45 minutes to an hour. I would like to visit you again at a time that is best for you, if I have additional questions, or to clarify what you said.

> I am also asking you to keep a short journal, to write 5 minutes each day, over a 1 to 2 week period, any thoughts and feelings you have about hope or your grief in general. If you prefer, I will provide you with a tape recorder and tapes to record your journal entries. With your permission, I would like to photocopy the journal and/or transcribe your taped entries and include your journal entries in the data analysis. At the second visit, I would like to talk about your journals and your general experiences of hope in bereavement. The total time for this study may be 3-4 hours (one hour per visit plus time to journal).

Potential 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 I will contact a Palliative Care Coordinator or your family doctor for you.

Potential Benefits:

> Taking part in this study will not benefit you directly, although some people have benefited from talking about their situation with a nurse. However, what you say may help others. The information will be used by health care professionals to provide better care for people in similar situations.

Storage of Data:

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

Confidentiality:

Your answers will be written down on a form, 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. Your written journals will be photocopied and/or transcribed, any personal information removed, and the originals returned to you. 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 in reporting the results of this study, 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:

Your participation is voluntary, and you may withdraw from the study for any reason, at any time, without penalty of any sort by telling me. It will not affect your care in any way. You may refuse to answer any individual question if you wish. You may withdraw your responses from the study after the interview by notifying me at any time, and your responses will be withdrawn, if possible. If you with draw from the study at any time, any data that you have contributed will be destroyed at your request.

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 **August 25, 2006**. Any questions regarding your rights as a participant may be addressed to that committee through the Ethics Office (306-966-2084). Out of town participants may call collect. If you would like to find out about the results of the study, please contact the researcher.

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, with the 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 B Demographic Form

The Experience of Hope in Bereaved Caregivers of Palliative Care Patients

Demographic Form

Date: _____ Code no.:_____

A. Participant (Caregiver Information)

 Age: _____ (years) Years of Education Completed: _____

Marital Status: M, D, W, S Religious Preference: _____

Occupation or previous occupation: _____

Ethnicity: Caucasian _____ First Nations/Metis: _____ Asian _____ Other: _____

Medical Information: (General health, hospitalizations since bereavement, visit to GP) _

_____

Current medication use, sleep problems: _____

_____

Living Arrangements: _____

Children: (Number, ages, proximity, contact) _____

_____

B. Palliative Care Patient

Age at death: _____ (years)   Gender: M____ F___

Medical Diagnoses: _____Date of death of the patient: _____

Length of Caregiving_____

Previous Caregiving Roles:_____

Circumstances of the death (location, general perceptions of the experience): _____

_____

 C. Current Social Support: _____

Appendix C Interview Guide

Initial Open-ended Questions: Feel free to begin where you like, you can go back as far as you think you need to or start with today if you like.

- What thoughts do you have about hope?
- What does hope mean for you right now?
- Have there been experiences of hope during the time since your spouse was dying?
- Have you noticed any changes in your hope? What did you do? What did hope feel like? What were the changes in your hope?
- Have there been individuals who influenced your hope? Tell me about how they enhanced or drained your hope.
- Tell me about a specific time when you had hope.
- What influences your hope to go up or down? What drains your hope?
- Has your view of hope changed since the death of your spouse? If so, how?

Optional Questions:

What is your hope for today?
What to do hope for in the future?
What happens if you don't have hope?
Who were/are the important people in your story of hope and bereavement?
What lessons have you learned about hope?
Can you teach someone else to have hope?

Final Questions:

Is there anything you would like to ask me?

Do you have anything to add?

What has it been like for you to participate in this research interview?

Appendix D Letter of Support

May 28, 2006

Ms. Lorraine Holtslander
College of Nursing
University of Saskatchewan
107 Wiggins Road
Saskatoon, Saskatchewan   S7N 5E5

Subject: Research Proposal: The Experience of Hope for the Older, Spousal, Bereaved
Palliative Caregiver

Dear Ms. Holtslander,

I am writing in support of the above research project to be conducted by you in
collaboration with Saskatoon Health Region Palliative Care Services.

Saskatoon Health Region Palliative Care Services involvement will be around the
recruitment of bereaved women aged 60 and over, who provided care to a spouse with
terminal cancer in the preceding year. Information gathered during the study will
contribute to a better understanding of the needs of primary caregivers providing
palliative care to their spouses at the end-of-life. Awareness of caregivers' experiences
of hope will inform the care and support offered to bereaved spousal caregivers through
Palliative Care Services.

Providing care to a partner at the end-of-life is a challenging undertaking that strains the
physical, emotional, psychosocial, and spiritual resources of the caregiver. Learning
about caregivers' experiences of hope during this time has implications for both primary
and formal caregivers in promoting positive caregiving experiences at the end-of-life
and healthy bereavement outcomes.

As Manager of Palliative Care Services for the Saskatoon Health Region I am pleased to
offer my support and to collaborate with you on this research project.

Sincerely,

Meredith A. Wild, R.N., M.N.
Manager, Palliative Care Services
Saskatoon Health Region
PCU, Level 5, St. Paul's Hospital
Saskatoon, SK, S7M 0Z9
Meredith.Wild@saskatoonhealthregion.ca

Appendix E: Guide for Participant Diaries

Please take five minutes at the beginning or end of each day, to reflect on hope.
Try to think about and describe what hope meant to you today. If you like, you could answer a few of these questions. Please don't feel obligated to answer any or all of these questions or even to journal if you don't feel like it.

- **What did hope feel like or look like today?**
- **Did anyone influence your hope today?**
- **Were there any specific actions, activities, or supports that enhanced your hope today?**
- **Did you have any challenges to your hope today?**
- **What gave you hope today?**
- **What did hope mean to you today?**

Please Note:
- **Try to focus on what you are going through right now.**
- **Don't worry about spelling or grammar**
- **Use point form if you like.**
- **In about two weeks, I will return and collect your journal for photocopying and/or transcribing. I will bring the original journal back to you to keep**
- **<u>As an option, I will supply you with a tape recorder and tapes if you prefer to speak your diary instead of writing it on paper.</u>**

Manuscripts

Holtslander, L. Searching for New Hope: A Grounded Theory of the Experience

of Hope for Older Women who are Bereaved Palliative Caregivers

Holtslander, L. The Psycho-Social Context of Bereavement for Older Women

who were Caregivers for a Spouse with Advanced Cancer

Date

Oncology Nursing Forum Editor
Rose Mary Carroll-Johnson, MN, RN
661-257-6932 (phone and fax)
ONFEditor@ons.org

Dear Editor,

I have submitted my manuscript titled: "Searching for new hope: A grounded theory of the experience of hope for older women who are bereaved palliative caregivers" electronically, for consideration of publication in Oncology Nursing Forum.

This manuscript describes the results of my dissertation research completed at the University of Saskatchewan, College of Nursing.

This paper is being submitted solely to this journal. The material in the paper is the result of original research, and has not been published previously, nor is it under consideration by any other journal.

Thank you for your consideration of this manuscript,

Sincerely,

Lorraine Holtslander, RN, MN, PhD(c)
Assistant Professor
College of Nursing, University of Saskatchewan
107 Wiggins Rd
Saskatoon, SK, S7N 5E5
Canada
306-229-6146

Running head: Grounded theory of hope

Searching For New Hope: A Grounded Theory of the

Experience of Hope for Older Women Who Are Bereaved

Palliative Caregivers

Submitted by:

Lorraine F Holtslander
Assistant Professor College of Nursing
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Abstract

Purpose/Objectives: To explore the experience and processes of hope for older women who are bereaved palliative caregivers and to develop a substantive theory of their hope experience.

Design/Research Approach: Qualitative, constructivist grounded theory

Setting: Participants' homes in a small Canadian city

Sample/Participants: Thirty interviews with thirteen women, ages 60-79, within the first year of bereavement after providing care to a spouse with terminal cancer, also twelve hope diaries

Methods/Methodologic Approach: Open-ended, in-depth audio-taped interviews, hope diaries, transcribed verbatim, and analyzed using constant comparative analysis

Main Research Variables: Participant's descriptions of their experience of hope

Findings: Participants defined hope as a gradual process of regaining inner strength and building self-confidence, to make sense of their totally changed situations. They were learning to stay positive, and move ahead with their lives. Hope was very important to the participants. The participants' main concern was losing hope which they dealt with by searching for new hope through finding balance, finding new perspectives, and finding new meaning and purpose. The theoretical model resembles a spiral and takes place within a social context.

Conclusions: Older women who are bereaved after caregiving for a palliative cancer patient are at risk for losing hope and are searching for new hope as they move through the complex processes of bereavement.

Implications for Nursing/Interpretation: Nurses can provide appropriate and effective care by monitoring women who are bereaved palliative caregivers at risk for losing hope and supporting them as they search for new hope and find their own way through bereavement.

Key Points:

1. Hope is an important variable and a psychosocial resource through grief and bereavement.

2. Older women are at risk for losing hope after providing care to a spouse with terminal cancer.

3. Bereaved palliative caregivers need support and understanding as they contend with losing hope and search for new hope through unique processes occurring within a complex social context.

Searching For New Hope: A Grounded Theory of the Experience of Hope for

Older Women Who Are Bereaved Palliative Caregivers

Many family caregivers face bereavement each year as the result of cancer

deaths, which are continuing to rise due to an increasing and aging population

(Canadian Cancer Society/National Cancer Institute of Canada, 2007). Family

caregivers face additional burden due to a lack of adequate support while caring for

hospice palliative patients (Canadian Hospice Palliative Care Association [CHPCA],

2007) as they provide increasingly complex care in the home (CHPCA, 2004), with

consequences known to affect physical and mental health in bereavement (Brazil,

Bedard, & Willison, 2003). Bereaved palliative caregivers have many unresolved

concerns, including intense grief (Grbich, Parker, & Maddocks, 2001), acute distress

(Jacob, 1996), and feeling a lack of support (Grbich et al., Hudson, 2006; Ingleton et al.,

2004; Jacob, 1996; Jansma, Schure, & Meyboom de Jong, 2005; Yurk, Morgan, Franey,

Stebner, & Lansky, 2002). Older female, spousal caregivers are at particular risk of

bereavement maladjustment (Ferrario, Cardillo, Vicario, Balzarini, & Zotti, 2004;

Gilbar & Ben-Zur, 2002).

Bereavement is a state of loss or deprivation, through death, usually followed by

grief (Attig, 2004). Hope is a personal resource that has fostered grief resolution, which

is the reconciliation to loss and a return to involvement with life (Herth, 1990; Hogan,

Morse, & Tason, 1996). Hope was also considered an essential process in bereavement

counseling (Cutcliffe, 2004b). Hope has been defined as a "multidimensional dynamic

life force characterized by a confident yet uncertain expectation of achieving a future

good, which to the hoping person is realistically possible and personally significant"

(Dufault & Martocchio, 1985, p. 380). Very little is known about the bereaved caregiver's experience of hope, except that it appears to be important in adjusting to bereavement. The overall purpose of this research was to explore the experience of hope for older women who are bereaved following caregiving for a family member with terminal cancer, and to develop a substantive theory to explain how these women resolve their concerns relating to hope in their lives.

Background

A review of the scientific literature, specific to bereaved palliative caregivers and hope, revealed that hope was an important variable in grief resolution and that very little research has been done focusing on the experience of hope for the palliative caregiver after the death of the patient. Only one reported study focused on hope during bereavement. It was a correlational study of hope, coping, concurrent losses, and setting to grief resolution for the elderly widow(er) (Herth, 1990). A stratified, random sample of 75 elderly persons, widowed 12-18 months after the death of a spouse in either hospital, hospice, or home, completed questionnaires on hope, grief, and coping, by mailed surveys. Their level of hope correlated positively to grief resolution and the use of self-reliant, confrontive coping styles.

Hope has been reported in the findings of research studies on bereavement. In a grounded theory study of the experience of bereavement, hope was identified as a source of consolation (Hogan et al., 1996). The researchers conducted telephone interviews with 34 participants, mostly younger women, from a wide range of experiences relating to the death of a loved one. During the phase of "being engulfed with suffering", described as the essence of grief, participants experienced despair,

hopelessness, and profound misery. The participants embraced hope as a way to find new meaning and purpose in spite of the death of the loved one. In another grounded theory inquiry with 12 participants who were bereavement counselors and ex-clients of bereavement counselors, the core variable of hope inspiration was the implicit projection of hope, experienced in a caring relationship between counselor and client (Cutcliffe, 2006a). Gaining hope was connected to a completed bereavement process, defined as experiencing a good or healthy ending to grief (Cutcliffe, 2006b). Cutcliffe's research focuses on inspiring hope in the bereavement counseling process and does not explain the meaning and inner processes of hope from the perspective of the person going through bereavement.

Current scientific knowledge about hope during bereavement remains descriptive and leaves gaps in our knowledge about the inner processes and meaning of hope for the bereaved palliative caregiver. A substantive theory is needed to guide research and practice with this population. Current theories of hope point to the critical importance of understanding the actions, processes, and conditions for hope, especially for people dealing with difficult life circumstances (Jevne, 2005), but do not explain the complexities of hope within a social context. Each theory provides insight into the processes of hope, but is based on research from differing methodologies, philosophies, and participant samples.

Research from the perspective of the bereaved palliative caregiver would increase the applicability, practicality, and usefulness of hope theories in guiding research and practice to meet the needs of this population. Older women who had cared for a spouse with cancer have unique needs and increasing age predicted more

difficulties with physical and mental health in bereavement (Brazil, Bedard, & Willison, 2002; Ferrario et al., 2004; Gilbar & Ben-Zur, 2002). The overall purpose of this study was to explore the experience of hope from the perspective of the older woman who is bereaved following caregiving for a spouse with terminal cancer. The specific aims were to explore the experience and processes of hope within a social context, to describe their definition of hope, and to construct a substantive theory of their hope experience.

Method

Design

A constructivist, grounded theory approach (Charmaz, 2006) was used to study the hope experience. This approach acknowledges subjectivity and the importance of social context and situations that impact the experience of the participants (Charmaz). Because of the limited research into the complexities of hope for this population and the process nature of both grief and hope (Cutcliffe, 2004a; Hogan et al., 1996), a constructivist grounded theory was well suited to the aims of the study.

Sample

Inclusion criteria for the sample were women: a) ages 60 and over, b) who resided with and provided care for a spouse with terminal cancer who died within the last year, c) English speaking, and d) freely consenting to be a participant in a research project about hope in bereavement. Exclusion criteria were: those cognitively impaired, non-autonomous, or not able to give a free and informed consent.

Purposive and theoretical sampling techniques were used to reach saturation. Saturation was defined as theoretical completeness or until no new properties of the categories or theoretical insights were being gained (Charmaz, 2006). Purposive

sampling encouraged diversity among the participants. For example, women were recruited to the study that had: a) a range of ages equal to and older than 60 years, b) different lengths of caregiving time, and c) various social support situations. The decision to seek participants with these specific characteristics was based on the scientific literature.

Theoretical sampling strategies were also used to narrow the focus of the data collection to the emerging categories in order to: a) develop and refine them, b) elaborate their meanings, c) discover variation, and d) define the gaps to find a full range of the experience of hope during bereavement. If possible, follow-up interviews were conducted on the emerging ideas, categories, and the processes to fully saturate the properties of the emerging grounded theory (Charmaz, 2006). Thirty interviews were completed with 13 participants. One participant was interviewed once and died before a second interview could be completed and seven were interviewed twice. Five participants were interviewed three times as they were good informants who provided insights to develop the properties of the concepts and fill theoretical gaps in the evolving theory. Hope diaries were completed by 12 participants and were included in the data analysis. Eleven diaries were written, one was taped. Three of the thirteen participants were having difficulty finding hope in their lives at the time of the interviews and were considered to be contrast cases; participants whose experiences seemed to challenge the emerging theory of hope (Charmaz). Their experiences and insights were examined further and integrated as an important source of variation in the emerging theory.

Procedures

This study was reviewed and received approval from an institutional review board and the local health region's ethics committee. Procedures for the protection of participants were strictly followed. The study took place in the homes of the participants of a small, western Canadian city, over a 10 month time period. The coordinator of volunteers for the in-patient palliative care unit identified potential participants, based on the inclusion criteria, and asked them if they would be willing to talk with a nurse researcher about the study. If they agreed, the researcher contacted the participants by telephone and arranged to meet with them in their homes to explain the study and to obtain a written, informed consent. One participant chose to be interviewed in the researcher's office at the university and this was accommodated.

Data collection involved a demographic form, face to face open-ended audio-taped interviews conducted by the researcher, written or audio-taped diaries from the participants, and the researcher's field notes and memos. The interview questions were formulated to give the participants an opportunity to provide the researcher with their own insights about hope and included: What thoughts do you have about hope? What does hope mean for you right now? Have you noticed any changes in your hope? The questions were changed as the study progressed to become more focused on the emerging theory. Also, each participant was asked to write in a diary over a 2 week period. They were given a prepared booklet, with instructions for completion inside, including: What did hope feel like or look like today? Did you have any challenges to your hope today? What did hope mean to you today? Field notes were made on the

setting, non-verbal behaviours, and the environment of the interviews. Memoing was used to preserve the researcher's ideas throughout the data analysis.

Data Analysis and Interpretation

Interviews were transcribed verbatim for analysis and the data were analyzed after each interview during data collection. Interview transcripts, field notes and memos, and the written or taped journals were entered into N6 software for the purposes of data storage and management. The data analysis consisted of Charmaz's (2006) methodology for initial, focused, and theoretical coding. Initial coding involved examining the data line by line, searching for categories, concepts, and patterns of behavior. Codes used the participants' language, or *in vivo* coding, to ensure the findings were grounded in the data. During focused coding the most significant or frequent initial codes were sorted, synthesized, integrated, and organized. Codes were developed into categories and incidents. Data were compared to data, categories to categories, and incident to incident, to develop the properties of the focused code. Constant comparison data analysis was used to move across the data, comparing data to the codes, categories, and incidents, to develop and refine the focused codes. Theoretical coding involved analyzing the focused codes and specifying the relationships between the categories and concepts. The focused codes were integrated and organized into a logical, coherent emerging theory of the bereaved palliative caregiver's experience of hope. Table 1 contains an example of the coding process.

Scientific rigor was sought through the specific criteria of credibility, originality, resonance, and usefulness to produce a constructivist grounded theory that has fit, work, relevance, and modifiability (Charmaz, 2006). Rich, in-depth data was gathered from

multiple sources including interviews, diaries, field notes, and memos, which were transcribed verbatim and coded line by line. The results of the interviews, and the emerging theory, were confirmed for resonance with the participants at second and third interviews. Grounding theoretical observations in the data and cross-coding and categorizing data ensured fittingness.

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

Demographic Data

Demographic characteristics of the participants are described in Table 2. The age of the participants ranged from 60 to 79 years. They were primarily Caucasian ethnicity. Seven were Protestant, three were Catholic, and three stated they had no religious preference. The length of caregiving varied across the sample, as did their current system of support.

Social Context

The data were collected within a social context of the participant's many losses, physical and emotional concerns, and the difficult relationships in their lives. The definition of hope and the substantive theory of hope are found within the participants' social contexts. The challenges of dealing with stressful relationships, financial concerns, difficulty sleeping, exhaustion from caregiving, and a lack of personal motivation, were some of the contextual concerns in which participants described their hope and social processes. A description of the social context of the participants is contained in another paper (Holtslander, 2007). Table 3 contains definitions and quotes to support the major findings from this study.

Defining Hope

  A definition of hope was inductively derived from the participant's experiences. The participants defined hope as a gradual process of regaining inner strength and building self-confidence to make sense of their totally changed situations. Hope was learning to stay positive and to move ahead with their lives. One participant wrote: "Hope meant having the courage and strength and self-confidence" and another wrote "I know I'll have bad days, but I know things will get better and easier", as they recognized within themselves, "it would be impossible to allow yourself to have any kind of life if you didn't have hope, like it would be....no sense to anything." They hoped to face each day, to gradually become stronger physically and emotionally, and to find a new meaning and purpose for their lives. One participant said: "Hope meant that someday I could go from grief to joy, to be able to have pride and regain my self-confidence."

  Hope was very important to the participants. One said: "...it is wonderful to have hope, because without that...I would have nothing, just nothing." Hope was an individual process that was always changing. One participant wrote in her diary: "Can't believe the number of ups and downs I have in a day since writing in this journal." Hope was also a choice, for example, one participant said:

  You know, the choice is yours, you know, you get up in the morning, you think

  'Well you know what…this is not going to be a very good day' and you can keep

  that in your mind and it cannot be a good day and then you think 'Oh, OK, I, I'm

  going to have a good day today', and you make yourself have a good day.

The participant's focus of hope was for themselves, for the future, and for their families. One said: "What do I hope for? Right now, I really hope that my health holds out, that I can be stronger emotionally." A participant wrote in her diary: "At this time, my hope is that we will be able to face each new day doing the best we can do and being able to cope without him....the hope I have for my family is the same as it always has been." Caregivers were also concerned about the future including their physical health, safety and well-being. A few very hopeful participants were looking towards new careers and new projects for the future, "I can only look to the future and try not to look back too often."

Losing Hope

A recurring concern of the participants, relating to the hope experience, was "losing hope". The participants described always having some hope but because they were losing hope, their hope was often shaky, uncertain, and at very low levels. One participant said: "you go through the pain and the tears and the memories of how ill he was so vivid in your mind, and it kind of brings you back down a little bit, and um progress that you've made, you may have lost it [hope] for a little while." Losing hope was a result of having to face an uncertain future filled with overwhelming losses including a loss of confidence, the loss of a partner, a caregiver, for some the loss of a home, loss of future plans, a loss of identity, and loss of meaning and purpose. A participant said: "but when you get at your lowest [hope] sometimes, you feel that way...I really don't want to go on, this really doesn't matter, I don't care."

During caregiving, the hope of the participants was based on the hope that their spouse would live. One described it as:

…so much to deal with, that, but you know through that whole year we both still had

hope...and you start hoping for so much, that I think that, uh, it's a disappointment

when at the end you realize that, we had hope, but we knew deep down in our hearts,

that it wouldn't be that long…

Losing hope began the deliberate process of searching for new hope in their lives, as one

participant said: "I know I have to make myself do more that helps to fill the void."

Another participant said: "Just keep it [hope] activated and keep going in the direction

of, I hope I have a better day tomorrow."

Searching for New Hope

Based on the main concern of losing hope, the overall basic social process the

participants used to deal with their concerns was "searching for new hope". The

participants were actively searching for new hope to fill the void in their lives. A

participant described it as: "I know I have to do something that fills the void...today I

found hope." The participants were searching for new hope using many different

processes. A participant described it as: "Hope does come in many different ways!" One

participant said: "Nothing comes easy, and you have to...work at everything...you know

maybe there is some hope for me somewhere down the road." The sub-processes of

searching for new hope were finding balance, finding new perspectives, and finding new

meaning and purpose. Figure 1 contains a diagram of the basic social process of

searching for new hope.

The theoretical model of the substantive theory of hope resembles a forward-

moving spiral demonstrating the active, energy and time-requiring, purposeful process

of searching for new hope. This basic social process, as shown in Figure 1, is

represented by an arrow indicating forward direction within the ups and downs of the spiral. The participants described actively making or forcing themselves do things to move ahead. One participant said: "...you kind of think to yourself well I've got to plan my day...I have to do something." The participants described times when they moved forward: "What gave me hope today: an invitation...I accepted, felt like a bit of a breakthrough." Each of the participants could be theoretically placed at various points in the spiral and it was necessary to go through each of the sub-processes in order to find new hope. The participants who were searching for new hope were moving along the spiral most days although there were inevitable setbacks that brought them back. One said: "It's funny how some days seem so good and other days not so good."

The participants described interconnected sub-processes of finding balance, finding new perspectives and finding new meaning and purpose. The definitions of the sub-processes and processes within each are described below.

1. Finding Balance. Finding balance was an important process to begin dealing with the negative, overwhelming, difficult emotions and experiences, that were draining hope, to find new hope in their lives. One participant described it as: "It's finding the balance. You know one day you can be so busy and then all of a sudden there's nothing." The participants described being "up one day, down the next," but "you are working towards balance." The ways to finding balance were finding hope in relationships, keeping busy, and releasing the pain. The hope in relationships provided an important source of strength, hope, and balance when their own hope was at a low level.

a. Finding hope in relationships was a necessary step to finding balance, especially when the participants felt unable to rely on their own hope. Specifically, the relationships were with family, friends, neighbours, spiritual supports, formal caregivers, their deceased spouse, and with pets. Support from family seemed to be the most important to the participants. One wrote in her diary, "Without her calls at least once a day-and all the support from everyone I don't know how I'd have got through." Spiritual support included faith and prayer. One said: "Sometimes what gives me hope is I have a lot of faith, and I do believe in the power of prayer." Some participants described being outside and connecting with nature as a source of spiritual support. The participants also described a relationship they maintained with their deceased spouse. One participant said: "I'm not really alone, he's always in my heart...I can almost feel him there." The participants described talking to their deceased spouse as a source of strength that enabled them to find a balance in their uncertain lives. The women who shared their lives with a pet described the importance of this relationship as giving them hope. Pets were a good reason to go outside for a walk and provided companionship through the days and nights. One said: "I avoided going out because coming home was hard. Except the dog greets me so I'm glad I have her..." The participants in this study appreciated the mailings of information and invitations to attend organized services for remembering their loved one. A participant wrote: "Hope today is knowing that the community shares in my loss, and I am grateful for the support, holding a remembrance service, helping all of us who lost loved ones this past year 'get past Christmas' this year and have hope in the future."

b. Keeping Busy. In order to keep a balance, the participants were taking steps to keep busy in order to find a balance with the negative thoughts and emotions and just get through the days. One wrote in her diary: "Hope today meant finding something to put my mind to." One participant wrote: "Today, I will keep as busy as possible and hope that in doing so another day will go by." One wrote in her diary: "Work and keeping busy is getting me through each day so far."

c. Releasing the pain. To keep a balance, it was important for the participants to talk about the loss and release their painful, difficult thoughts and emotions. A participant wrote this: "...to talk about our losses. Maybe this is where hope enters our lives as between us we can try to comfort each other." One participant wrote in her diary: "no moping around – if loneliness overwhelms me and memories cause tears-have a good cry and cleanse your soul. Then get on with life." Releasing negative emotions and thoughts was important to finding balance and new hope.

2. Finding New Perspectives. After finding a balance, the participants were able to begin finding new perspectives, as they deliberately refocused from the loss towards facing a new reality, consciously realizing when things were going bad and how they could be improved. A participant said: "You put things into perspective." Another said: "You have to be able to look for that light because we can stay in that darkness." After reflecting on hope in her diary, a participant wrote: "Think positive and things are better!" The sub-processes that participants used to find a new perspective were "letting go of the past", "being grateful", and "staying positive"

a. Letting Go of the Past. After many years of sharing a life with someone, it was very difficult to let go of the past. One participant said: "...it's just

difficult to let it go...life has changed" she also said: "you don't want to lose what you

had, and yet you do know better...you have to let go because, it's not the same." Another

participant described it as: "You close chapters and you start new ones" and "I guess it's

your own decision whether life is a bowl of cherries or just the pits! It was a great day,

and although my heart aches for (spouse's name), I still feel good."

b. Being Grateful: One participant wrote in her diary: "The first step to

hope is being thankful." Another said: "Appreciating the supportive people in your life,

counting our blessings that our lives can go on, if we make the effort to carry on." Being

thankful helped the bereaved caregivers to find new perspectives in their situation. "I

know I'll have bad days, but I also know things will get better and easier and I should be

grateful I'm here to feel them both."

c. Staying Positive. The participants talked about hope and the

importance of staying positive. One participant who was usually hopeful said: "Well, I

try and keep positive about things, you know everything." Another said: "I like to stay

positive." By writing about hope in a diary, some participants gained insights into their

own ability to stay positive. One said: "I just looked at it (the diary), and I thought my

goodness, it's pretty glum, there wasn't too many up and up moments." Another

participant talked about keeping a diary and how it helped her to reflect and find a new

perspective: "...and then I found the more I wrote every day and I think some days I

wrote a lot, I found it easier and I, I started feeling better."

3. Finding New Meaning and Purpose: As the participants worked through

finding balance and finding new perspectives they were able to progress towards filling

their days with new hope by finding new meaning and purpose for their lives. One said:

"I do think I need to find a purpose." Another reflected on participating in the study: "I hope I've helped you, but I think its helped me a great deal, as well as the need to help someone, if someone needs me, I can be there for them...I felt good about it...I wasn't negative at all." The sub-processes of finding meaning and purpose were "taking control a little bit", "helping others" and "looking to the future".

   a. Taking control a little bit. The participants started to find new meaning and purpose by deliberately taking some control of their lives. One was: "taking control a little bit even if it's only for a few hours. You know, you give your life a little bit of purpose, and I think it helps." One participant stressed the importance of: "Plan one thing for the day even if its' only taking out the garbage!"

   b. Helping Others. The participants who were moving along the spiral were able to reach out to others in order to find meaning and purpose. One participant helped a neighbor who was actively caregiving: "I was able to listen…and felt I had been able to help her by being a sounding board" as a result the caregiver had a: "Very happy, upbeat day today!" She wrote about the keeping a diary:

  I have learned a lot about myself, how to deal with problems I encounter and how to relax and enjoy each minute of each day. My HOPE is that something in this diary will be of help to others and both people who are grieving and people who are trying to help them will have a better understanding of the process.

Another participant said: "I hope that today I will be able to, when I lie down at night that I can look back and say, it was worthwhile for me to be here."

   c. Looking to the Future. Some of the participants were starting to actively plan for the future however the participants who could be considered contrast

cases were looking ahead to find more emptiness and were having difficulty with this

sub-process. One wrote in her diary: "I think any hope I have for the future will be in

watching my grandchildren grow and mature, taking part in their lives and being there

for all of them if they need me." Another said: "...hope for the future, yeah, because I've

got children and I've got grandchildren." She was also starting to find hope in a new

career: "I mean, I have hope for the future...I'm just starting out on this voice thing."

The participants who were looking forward to the future were those who had gone

through the other sub-processes along the spiral of searching for new hope.

The substantive theory "searching for new hope" describes the experiences of

the participants in this study as they deal with the challenges of losing hope by finding

balance, a new perspective, and new meaning and purpose during bereavement. The

processes and sub-processes in the forward-moving spiral are depicted in the diagram as

a continuous process of searching for new hope. The participants who emerged from the

data as contrast cases provided insight into the challenges of one of the sub-processes,

finding balance, especially when support is inadequate and difficult relationships are

causing a loss of hope. Aspects of the social context, such as physical concerns and

other secondary losses also resulted in difficulty moving along the spiral. As one

participant said: "I haven't found anything positive yet...it's one year and I don't think I

feel anymore hopeful than I did…a year ago. I really don't."

<center>Discussion</center>

The participants in the study identified "losing hope" as their main concern

related to hope during bereavement after caregiving for a spouse with terminal cancer.

"Searching for new hope" was the basic social process used to deal with losing hope,

conceptually illustrated as forward movement through a spiral. The sub-processes of searching for new hope were "finding balance", "finding new perspectives", and "finding new meaning and purpose." The findings that emerged in this constructivist grounded theory study are unique when compared to previous research, since hope has not been studied from the perspective of the bereaved palliative caregiver with the same methodology. However, similar individual concepts were found in other research studies with bereaved persons and palliative caregivers.

Defining Hope

A definition of hope was inductively derived as a gradual process of regaining inner strength and building self-confidence to make sense of their totally changed situations. Hope involved learning to stay positive and to move ahead with their lives. This definition of hope has not been found in the literature although some aspects of the definition have been described in other research. Hope was a source of consolation in grief and involved gaining confidence for getting on with life (Hogan et al., 1996). Hope as inner strength was described in research with active palliative caregivers (Holtslander, Duggleby, Williams, & Wright, 2005). Hope as having confidence is included in the definition of hope by Dufault and Martocchio (1985).

Another finding that is similar to other research studies is the importance of hope in the participants' lives. Hogan et al. (1996) and Herth (1990) described hope as important to grief resolution. Hope was described by the participants as always changing and a choice. In previous studies with palliative caregivers, who were not bereaved, hope was also described as a choice and had many fluctuations (Holtslander et al., 2005).

The participants in this study could be theoretically placed along the spiral depicted in Figure 1, which had upward and downward movement. The participants described where they would be on the spiral based on their social context and their ability to find balance, a new perspective, and new meaning and purpose for their lives. For example, a few participants were actively finding new meaning and purpose by taking control a little bit, helping others, and were looking to the future. Others were focused on finding balance. The overall continuous processes of searching for new hope are unique in the literature. The forward-moving spiral has similarities to the dual-process model of grief (Stroebe & Schut, 1999), where oscillation between loss and restoration was a positive pattern of coping after the loss of a spouse. Stroebe and Schut concur with the importance of social context when exploring the processes of coping with grief for each bereaved person.

Losing Hope

The participants described their main concern as losing hope. Losing hope is similar to another study of hope and bereavement counseling; bereaved persons experiencing complicated grief were found to be in particular need of hope (Cutcliffe, 2006b). Dufault and Martocchio identified going through a loss as an opportunity for the activation of the hoping process or as a test of hope (1985). This supports the current results, where the main concern of losing hope started the processes of searching for new hope.

Searching for New Hope

Searching for new hope was an active, purposeful activity, unique to each person. This finding has not been seen in previous research with bereaved persons;

however, in hope research with caregivers of people with HIV/AIDS, the basic process

was identified as a searching for one's own way (Kylmä, Vehviläinen-Julkunen, &

Lähdevirta, 2003). Although not the same as searching for new hope, the process of

"searching" was a key process of hope in difficult circumstances.

Finding Balance

Finding balance was a necessary first step towards searching for new hope. It

was an important process to deal with the negative emotions and experiences that were

draining hope by relying on others for support, while keeping busy, and releasing the

pain. The support of others has been described as the essence of hope (Cutcliffe, 2006a),

and weekly visit from friends and family were correlated with increased hope in elderly

widow(er)s (Herth, 1990). Relatives and friends played an important role in the recovery

from bereavement (Brazil et al., 2003). Although relying on others was a finding in

these studies, finding balance was not described. This may be because of methodology

used in the studies was descriptive and quantitative, while the current research was a

search for processes and how the support of others affected the processes of hope.

Keeping busy, a sub-process of keeping balance is similar to the distraction,

denial, and avoidance included as aspects of restoration-oriented coping in the dual-

process model of coping with bereavement (Stroebe & Schut, 1999). In this model,

adaptive coping during grief involves a constant back and forth oscillation between loss

and restoration processes, contributing to healthy coping with loss, similar to the process

of finding balance. Further research was done applying this model by measuring an

inventory of oscillation activities with 163 bereaved widow(er)s (Caserta & Lund,

2007); having a balance between the processes was associated with more positive

outcomes, similar to the current study where finding balance was needed in order to find hope.

Finding New Perspectives

Finding new perspectives was a deliberate refocusing from the loss towards facing a new reality described by the study participants as letting go of the past, being grateful, and staying positive. These concepts were found in previous research by Hogan et al. (1996) who described the processes of letting go of the past in order to actively engage with life during bereavement, which may be similar to finding new perspective by letting go and staying positive. Also research with 45 caregivers, bereaved for two months, found most were coping well and could identify positive outcomes during bereavement (Hudson, 2006); however, 26% were not coping well, which concurs with the participants in this study who were unable to find new perspectives and were struggling to find balance.

Finding New Meaning and Purpose

Taking control a little bit, helping others, and looking to the future were identified by the participants as ways to find new meaning and purpose. Similarly, finding new meaning and purpose by helping others and experiencing personal growth were important to getting through bereavement (Hogan et al., 1996). Also, in a sample of 506 younger, bereaved adults, high levels of meaning-making predicted better bereavement outcomes (Neimeyer, Baldwin, & Gillies, 2006). Personal growth, a change in life perspective, and strengthening relationships were processes in meaning-making in a longitudinal study involving 205 bereaved caregivers of people with terminal illnesses. Those who were able to find positive benefit during bereavement

showed significantly improved emotional outcomes (Davis & Nolen-Hoeksema, 2001).

Finding new meaning and purpose as a process farther along the spiral of searching for

new hope, occurring after finding balance and new perspective, is unique in the

literature, since the processes of hope have not been studied from a qualitative, insider's

perspective for this unique population, and considering the importance of their social

context.

Factors Influencing the Study Findings

The context of the study, the methodology, and the sample had an impact on the

findings of this study. The participants were receiving support from a readily accessible

health care system, both during caregiving and into the time of bereavement, which may

have influenced their experience of hope. The sample was a relatively homogenous

sample of older women who were bereaved following caregiving for a spouse with

cancer in western Canada, although efforts were made for heterogeneity using purposive

and theoretical sampling. People from different ethnic and religious groups,

socioeconomic status, cultural groups, gender, or geographic locations may describe

their hope experience differently. The participants were willing to speak to a nurse

researcher about hope; those finding it difficult to talk or not interested in participating,

were not included in the study, which may have affected the results. The sample was

bereaved caregivers of a cancer patient who experience a unique trajectory at the end of

life (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003). As well older women have

unique concerns including many secondary losses and physical changes which impact

the study results. Thus future research should be done with other groups of caregivers.

Also, the methodological approach was a constructivist grounded theory which

identified social processes. Different methodology would result in different results which would add to the emerging theory of: "Searching for New Hope". The findings of this study need to be interpreted considering these factors.

Implications for Practice and Research

The findings of this study offer a unique insight into the bereaved palliative caregiver's experience of hope that may provide a foundation for future research to develop theory-based interventions, programs of support, and policies of care to promote healthy and safe outcomes through the difficult transition after caregiving into bereavement. As this is an emerging theory, more research is needed with older women of various cultural and ethnic groups and geographic locations. Additional studies with younger women in differing social contexts would add to the understanding of hope of women. Also, further research is needed to develop the concepts and processes described in the findings of this study.

Most caregivers of terminally ill cancer patients are older women, facing unique challenges within a complex social context of difficult relationships, multiple losses, and physical and emotional concerns. Women who are bereaved caregivers may present in primary care situations, require services for their health care needs, arrive at support groups, or may be involved in a bereavement follow up program. They may be having difficulty with losing hope, and are looking for understanding, balance, a new perspective, and a meaning and purpose for their lives. Health care professionals could through assessment, identify where they are on the spiral. Their need for hope cannot be underestimated. Assessing their level of support and difficulties finding balance may identify those at particular risk for loss of hope. Possible interventions may include

talking about their caregiving experience, finding release for the pain, referral to appropriate supports, guided journaling, or just being encouraged as they find their unique way through grief with the ultimate goal of promoting healthy and positive bereavement outcomes. Those who are finding new meaning and purpose during widowhood need to be recognized and supported.

Conclusion

Providing care and support for bereaved family caregivers is a necessary, yet often neglected aspect of the mandate of palliative care services, which is to offer support to families facing life-threatening illnesses, that extends into the time of bereavement (World Health Organization, 2002). Understanding the experience of bereavement and providing compassionate support has been identified as the most important factor in all bereavement interventions (Jordan & Neimeyer, 2003). Health care professionals are in a strategic position to offer care and support to people journeying through bereavement by fostering hope.

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Table 1

Demographic Characteristics of the Participants

Characteristics	Number
Age:	
60-69 years	7
70-79 years	6
Ethnicity:	
Caucasian	13
Religious Preference:	
Protestant	7
None	3
Catholic	3
Years of Education Completed:	
8-12 years:	7
13-16 years:	6
Primary Diagnosis of Patient:	
Lung Cancer	3
Unsure of primary	3
Lymphoma:	2
Pancreatic Cancer	2
Prostate Cancer	2
Kidney cancer	1
Length of Caregiving:	
1-3 months	3
4-6 months	4
7-12 months	3
More than 12 months	3
Main Support System:	
Children close by	6
Children out of town	3
Friends	2
Other relatives	2
Months Since Death of the Patient:	
3-6 months	3
7-9 months	7
10-13 months	3

Source: Author

Table 2

Example of the Coding Process

Transcripts	Incidents	Categories	Concept
can you ever come back and have that same confidence that you had before	Loss of confidence	Main Concern	Losing Hope
it's a very unsecure future really	Loss of security in the future		
There's not much hope for me	Low level of hope	Losing hope	
You may have lost it [hope] for a little while	Loss of hope		Searching for new hope
I hope I have a better day tomorrow	Hope for tomorrow		
Hope today meant finding something to put my mind to	Finding your hope	Searching for hope	
I know I have to make myself do more that helps to fill the void	Filling the void		
Hope does come in many different ways	Many ways to find hope		

Source: Author

Table 3

Quotes to Support the Definition and Processes of Hope

Meaning, Action, Process	Definition	Quotes to Support
Defining Hope	Hope was defined by the participants as a gradual process of regaining inner strength and building self-confidence to make sense of their totally changed situations. Hope was learning to stay positive and to move ahead with their lives."	"I know I'll have bad days, but I know things will get better and easier." "Hopefully after every "first" passes it will get easier." "To have pride and regain my self-confidence." "Hope meant having the courage and strength and self-confidence" "I felt positive and hopeful." "Knowing that life will still go on, and I had to try and make the best of it-for me and for my family." "Hope that life will be happy again." "It would be impossible to allow yourself have any kind of life if you didn't have hope. Like it would be uh it would be uh no sense to anything."
Losing Hope	The participants described always having some hope but because they were losing hope, their hope was often shaky, uncertain, and at very low levels.	"There's not much hope for me." "It's [hope] not active enough, not yet but um, no the hope is there." "You go through the pain and the tears and the memories of how ill he was so vivid in your mind, and it kind of brings you back down a little bit … you may have lost it [hope] for a little." "but when you get at your lowest [hope] sometimes,

		uh you feel that way, you just feel that way you say well I don't know I really don't want to go on, this really doesn't matter, I don't care, "Just to keep it [hope] activated and keep going in that direction of, of, I hope I have a better day tomorrow."
Searching for new hope	The participants handled losing hope by actively searching for new hope to fill the void in their lives. It required energy and purpose.	"Nothing comes easy, and you have to, you have to work at everything...you know maybe there is some hope for me somewhere down the road." "Hoping tomorrow will be better." "Do I dare hope for a little more for tomorrow?" "I know I have to make myself do something that fills the void…today I found hope." "I'm looking forward. It gives me hope."
Finding balance	Finding balance was an important process to begin dealing with the negative, overwhelming, difficult emotions and experiences, that were draining hope, to find new hope in their lives.	"It's finding the balance. You know like you can be so busy and then all of a sudden there's nothing." "Up one day, down the next." "You are working towards balance." "I can only look to the future and try not to look back too often." "And sometimes it's like I'm just at the threshold but I know better I know enough to pull myself back up, and I think that's where my hope for the future

		lies."
Finding new perspectives	Deliberately refocusing from the loss towards facing a new reality, consciously realizing when things were going bad and how they could be improved.	"You put things into perspective." "It's very hard to, very hard to put a lot of things into perspective." "You have to be able to look for that light because we can stay in that darkness." "Think positive and things are better."
Finding new meaning and purpose	The experience of losing hope prompted participants to move ahead and fill their days with new hope by finding new meaning and purpose.	"I think I need to find a purpose." "My hope is that something in this diary will be of help to others." "I hope I've helped you, but I think its helped me a great deal, as well the need to help someone, if someone needs me, I can be there for them, and um it was OK, I felt good, I felt good about it...I wasn't negative at all."

Figure 1. The Basic Social Process of Searching for New Hope

Finding Balance
• Finding Hope in
  Relationships
• Keeping Busy
• Releasing the Pain

Finding New
Perspectives
• Letting Go of the Past
• Being Grateful
• Staying Positive

Finding New Meaning
and Purpose
• Taking Control a Little Bit
• Helping Others
• Looking to the Future

Searching for
New Hope

Losing Hope

Social Context
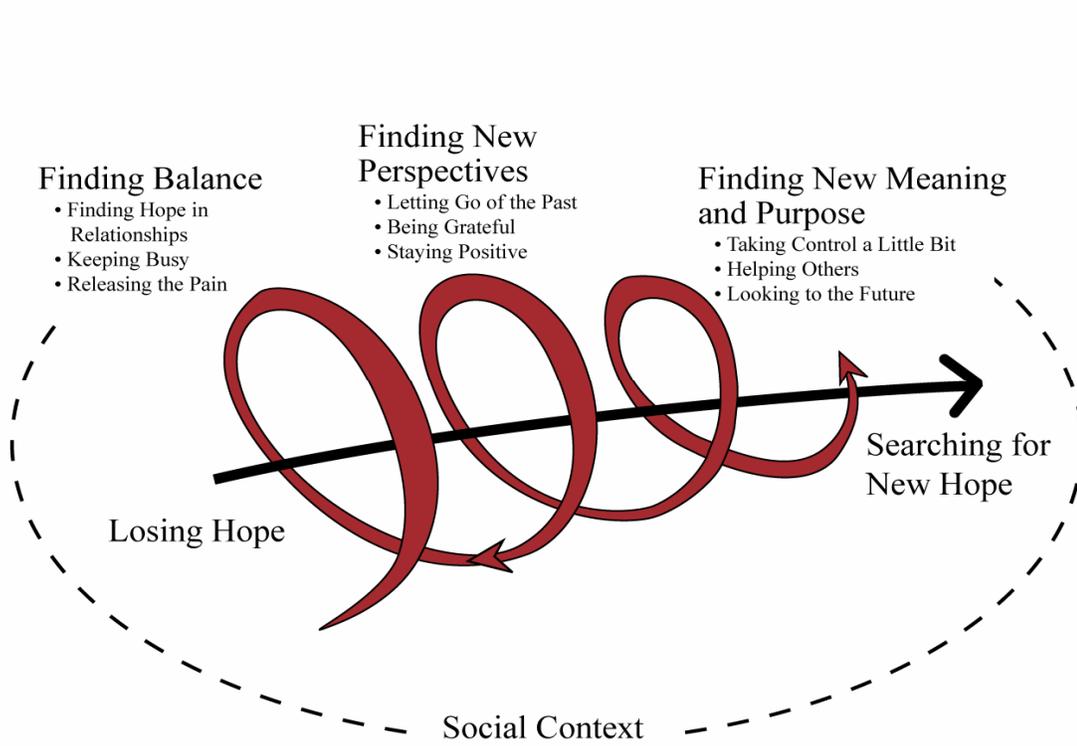
Source: Author

Date

Editor, Sandra P. Thomas
University of Tennessee
1200 Volun-teer Blvd., Knoxville, TN 37996, USA
sthomas@utk.edu.

Dear Editor,

Please find enclosed for your review the original and two copies of the manuscript, which was also sent electronically to stthomas@utk.edu, titled: "The Psycho-Social Context of Bereavement for Older Women who were Caregivers for a Palliative Cancer Patient".

The manuscript has been formatted with MS Word.

This manuscript is a result of my dissertation research at the University of Saskatchewan, College of Nursing. I hope that you will consider this manuscript for publication in the journal: Issues in Mental Health Nursing. It has not been published elsewhere and has not been submitted simultaneously for publication to any other journal.

Sincerely,

Lorraine Holtslander, RN, MN, PhD(c)
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College of Nursing
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107 Wiggins Rd, Saskatoon, SK, S7N 5E5
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Running head: Psycho-Social Context of Bereavement

The Psycho-Social Context of Bereavement for Older

Women who were Caregivers for a Spouse with Advanced

Cancer

Submitted by:

Lorraine F Holtslander

University of Saskatchewan, College of Nursing

Abstract

Purpose: To explore the psycho-social context of bereavement for older women who were caregivers for a spouse with advanced cancer.

Design: Qualitative, exploratory

Participants: Thirty interviews, 13 older women, 12 diaries

Methods: Constant comparative analysis

Findings: Psycho-social context included the **intrapersonal**: loneliness, pain, and exhaustion. **Interpersonal** involved a new way of life as a single person and difficult relationships. The **community/societal** context included a loss of identity, pressure to move on, financial concerns, difficult seasons and relying on formal supports.

Conclusions: The psycho-social context of this group of women is unique and must be considered when providing care and programs of support.

The Psycho-Social Context of Bereavement for Older

Women who were Caregivers for a Spouse with Advanced

Cancer

Current mortality rates indicate 24% of women and 28% of men, or

approximately one out of every four Canadians, will die from cancer (Canadian Cancer

Society/National Cancer Institute of Canada, 2007). Many women will provide care for

a spouse with cancer and then face the challenge of adjusting to widowhood while

recovering from the exhaustion of caregiving. Older women play key roles in providing

informal care for palliative cancer patients. Because of changes in the health care

system, family caregivers are expected to provide increasingly complex and technical

personal and medical care in the home, with a lack of required resources to support

community care (Canadian Hospice Palliative Care Association, 2004). A difficult

caregiving experience had physical and mental health consequences in bereavement

(Brazil, Bedard, & Willison, 2003; Grande, Farquhar, & Barclay, 2004), especially for

older women who have lost a spouse (Ferrario, Cardillo, Vicario, Balzarini, & Zotti,

2004).

This paper reports the results of a secondary thematic analysis of data that were

collected for a constructivist grounded theory study of older women who are bereaved

following caregiving for a spouse with terminal cancer (Holtslander, 2007). Key aspects

of this population's psycho-social context of bereavement emerged from the data. Since

the dynamic process of bereavement does not occur apart from the social/interpersonal

context of each bereaved person (Stroebe & Schut, 1999), examining the social setting

for bereavement will provide insight into the intra- and interpersonal aspects of this

process. For the purposes of this paper, the psycho-social context of bereavement is

defined as an intricate web of intra- and inter-personal relationships, including social,

historical, and interactional contexts (Charmaz, 2006) and situations or settings that

surround and affect the bereavement process for this specified group of people. Older

women who are bereaved following caregiving for a spouse with terminal cancer have a

unique social context, requiring insight and understanding in order to effectively meet

their needs.

Background

The experiences of caregiving may have an impact on the bereavement process.

Bereavement is defined as the loss, through death, of someone significant which may be

associated with severe consequences on health and well-being (Stroebe, Hansson,

Stroebe, & Schut, 2001). A death from cancer is usually an intense, challenging

trajectory of decline, with difficult to manage symptoms and obvious declines in

physical functioning (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003). Caregivers who

had a difficult experience during the caregiving time had a poorer recovery in

bereavement (Brazil et al., 2003; Gilbar & Ben-Zur, 2002; Kris et al., 2006). In a study

of 93 caregivers, bereavement maladjustment problems correlated with perceptions of

emotional distress (Ferrario et al., 2004); older, female spouses and those who

experienced a substantial emotional burden proved to be at greater long-term risk.

Bereaved family caregivers of cancer patients describe their experience of

overwhelming emotions, and a lack of support (Grbich, Parker, & Maddocks, 2001;

Hudson, 2006; Kristjanson, Cousins, Smith, & Lewin, 2005; McLaughlin, Sullivan, &

Hasson, 2007). Depression (Wyatt, Friedman, Given, & Given, 1999), loss of appetite

(Brazil et al., 2003), sleep problems (Carter, 2005), poor health (Kristjanson et al., 2005), distressing grief over an unpredictable length of time (Chentsova-Dutton et al., 2002), and higher rates of death during bereavement (Christakis & Iwashyna, 2003) have been reported in studies with bereaved caregivers of cancer patients.

The context of bereavement for caregivers of palliative cancer patients is different than the experience of caregivers who went through other illness trajectories prior to bereavement. For example, unlike family caregivers of persons with cancer, family caregivers of dementia patients frequently experienced relief at the end of caregiving (Schulz et al., 2003), which may have included stressful events such as nursing home placement (Meuser & Marwit, 2001), and a lengthy caregiving experience (Boerner, Schulz, & Horowitz, 2004; Grant et al., 2002; Robinson-Whelen, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001). In a study of 217 bereaved caregivers of dementia patients, 72% expressed feelings of relief following the death of the patient and rates of depression decreased (Schulz et al., 2003). It is unclear if these differences are the result of the illness trajectory of the family member during caregiving or if other factors such as relationships and support may be involved. These studies suggest however, that the needs and experience of bereaved caregivers of persons with cancer may be different than the needs and experience of bereavement following other caregiving experiences. Research providing an understanding of the psycho-social context of bereavement for the spouse of a palliative cancer patient may be used to guide practice and policy in order to meet the needs of this unique group.

The current study addresses the gaps in the literature which describe the difficulties caregivers experience during bereavement but lack insight into the effects of

their social context. Research investigating the experience of older women who are bereaved caregivers, from a qualitative, "insider's" perspective, will add to the scientific knowledge base needed to provide and evaluate programs of support and address the needs of this population. The overall purpose of this paper is to explore and describe the psycho-social context of older women who are bereaved following caregiving for a palliative cancer patient.

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

Design

During initial coding of the data from the grounded theory study of hope (Holtslander, 2007), the importance of psycho-social context emerged as an unexpected finding impacting the experience of hope. As described by Charmaz (2006), a grounded theory is based in the social context and situation of the participants. Constant comparative methods were used to analyze the data to describe in detail the psycho-social context of the bereaved palliative caregivers who were participants in this study.

Sample

The sample for the study was older, female, spousal caregivers of a deceased palliative cancer patient. Inclusion criteria were: women ages 60 and over, who previously resided with and provided care for a spouse with terminal cancer who died within the last year, English speaking, and freely consenting to be a participant in a research project about hope in bereavement. Exclusion criteria were: those cognitively impaired, non-autonomous, or not able to give a free and informed consent.

Purposive sampling was used to select 13 participants for this study from a variety of ages over 60, length of caregiving, and available supports. These categories

were based on a review of the literature. Each participant was interviewed twice, except for one who died before a second interview could be arranged, and five were interviewed three times. Thirty interviews were completed. The participants were also asked to keep a diary over a two week period; 12 diaries were collected, photocopied or transcribed, and returned to the participants. Eleven diaries were written, one was taped. Saturation was reached as no new themes were emerging from the data. Table 1 outlines the demographic characteristics of the participants in this study.

Procedures

The study was approved by an institutional review board and the local health region's ethics committee. Procedures to ensure informed consent and participant confidentiality were strictly adhered to. The coordinator of volunteers for the in-patient unit of the local health region's palliative care program, identified potential participants, based on the inclusion criteria, and asked if they would be willing to talk with a nurse researcher about the study. The volunteer coordinator notified the researcher of potential participants. The participants were then contacted by the researcher to arrange a time to meet with them in their home. The study was explained and a written, informed consent was obtained prior to the first interview.

Participants were interviewed in their homes by the researcher. One participant chose to be interviewed in the researcher's office. Demographic data were collected prior to the first interview. Open-ended audio taped interviews were conducted with each participant. These interviews lasted approximately 20 to 60 minutes. Field notes were also made on the setting, non-verbal behaviours, and memos of the researcher's thoughts and feelings about the interview. The participants were asked to keep a diary

each day for a period of two weeks. The researcher returned for a second interview, collected the diary, photocopied and transcribed it and returned it to the participants by mail or at the third interview.

Interviews, diaries, field notes, and memos were audio-taped, transcribed verbatim, and entered into N6 software for the purposes of organizing the data. A thematic analysis of the data was completed to reveal the study findings. Open-ended interview questions were intended to give the participants an opportunity to talk about their experiences during bereavement and to discuss any issue they felt relevant. This paper reports the data that emerged regarding the participant's psycho-social context of bereavement.

Data Analysis

Data were transcribed from the audio recordings, diaries, field notes, and memos, and were analyzed during data collection using constant comparative methods. The data were entered into N6 software for the purposes of managing and coding the data. The data were analyzed and categorized into intrapersonal, interpersonal and social/community categories to present the complexities of the psycho-social context of the participants. Within these categories, themes were developed using the words of the participants, in order to stay close to the data. An overall theme representing each of the categories was then chosen. Quality and credibility was sought by gathering rich data from multiple sources and transcribing the interviews and diaries verbatim. The data, field notes, and memos, provided an audit trail of the research, from the raw data to analysis and interpretation. The results of each interview were confirmed with the participants at second and third interviews.

Results

Demographic Data

Table 1 contains the specific demographic characteristics of this sample. The participants ranged in age from 60-79 years. This represented a broad range of ages within the defined segment of older women. They were primarily Caucasian ethnicity. Seven were Protestant, three were Catholic, and three stated they had no religious preference. Length of caregiving varied in the sample, three had been caregivers for less than three months, four for four to six months, and six for more than seven months. These demographic characteristics had a great impact on the psycho-social context of their experience of bereavement; for example increasing age was associated with more physical health challenges and the length and experience of caregiving impacted their ability to recover and find a new identity.

Psycho-Social Context

The psycho-social context of the bereavement experience for the participants in this study is depicted in Figure 1, as a series of interrelated, spiraling circles, each directly influencing the experience of bereavement of the older women in this study. The diagram includes the intrapersonal, interpersonal, and community/societal circles of context surrounding the woman who is bereaved. The intrapersonal context includes the major life challenges resulting from the caregiving experience and the loss of a spouse such as loneliness, pain, exhaustion from caregiving, and a range of physical and emotional concerns occurring within the woman who is bereaved. The interpersonal social context occurs between the woman who is bereaved and people close to her and includes adjusting to life alone, needing support, and dealing with difficult relationships.

Interactions with the community and society in general form the outermost circle of the

social context of bereavement and include a loss of identity, a new role as a widow,

having to move, feeling pressured to get over the difficulties they were experiencing,

reacting to difficult seasons in the year, while receiving support from the community

and the health care system.

Intra-personal Context: "Losing a part of yourself"

The overall theme of the intrapersonal context for the participants in this study

was described as "losing a part of yourself." This meant having to go through the pain

and loneliness of losing a life partner. One participant summed it up this way: "We were

married for fifty-nine years... (it's) just like somebody comes and….chopped your arm

off." Another participant said: "I'm hoping I won't always feel so much pain and

emptiness." The sub themes of "losing a part of yourself" were loneliness, emptiness,

pain, vivid memories and general exhaustion from caregiving, a lack of motivation,

insecurity, loss of a partner and caregiver, and physical and emotional challenges.

Participants described the exhaustion, vivid memories, and their current physical

health problems that were a result of a lengthy and difficult caregiving experience. One

participant said: "I think as a caregiver you go, go, go, go, go, go and then um…you sort

of lost yourself along the way, haven't you?...you do and…you don't think of yourself

'cause you were…a caregiver…" The experience of caregiving was still affecting them,

as one participant said: "you go through the pain and the tears and the memories of how

ill he was."

The participants had many physical concerns during bereavement including

difficulty sleeping, dealing with chronic illness, and weight changes. It was difficult to

learn to sleep alone, as one participant described it: "…that initial crawling into bed and being alone." Other general health concerns were raised. A participant said: "…the other thing that bothers me and I'm sure it bothers other ladies too, is your health, you know I mean what if your health gets bad? What if you get sick? …I haven't done anything about my health for a long time." One participant discussed her concerns about her heart and the possibility of having surgery. The researcher discovered her obituary notice in the local newspaper as having "died suddenly". One participant wrote in her diary about the impact of losing a caregiver: "these are the times I really miss my (spouse's name) he drove me to every Dr appt-waited and fretted with me."

The participants experienced a range of emotional concerns including anxiety, sadness, difficulty concentrating, a lack of motivation, and uncontrollable emotional reactions. One participant wrote about her difficulties with anxiety: "I hate when this gets a hold on me…it is exhausting to beat yourself up during the day." It was difficult for the participants to force themselves to go out again. One said: "I just feel I'm not ready, I'm definitely not ready emotionally…I'm finding that I'm staying away from, from going to places where I know a lot of people." Most participants felt overwhelming sadness. One stated: "It's hard to feel happy." Another said: "I mean you always feel, like I do anyway, that there's that big black hole there, and I've just got to keep out of it, you know, I can't allow myself to slip into it, I think that's the depression hole probably." Regarding emotional reactions, one participant said: "yeah, and it comes upon you at different times, like you don't expect it, like nothing has to happen, I mean I can walk out of another room and into a different room and all of a sudden its just a, you know, a real, its an overwhelming sadness, and then it goes away."

Interpersonal Context: "Striking Out Alone"

The overall theme of the interpersonal social context of the participants was "striking out alone". Participants described this as finding themselves in a new way of life as a single person. They were also needing the support of others and dealing with difficult relationships. All of the participants were now living alone. One participant described the change as: "…things you planned to do together and you never worried because you had the other person, I mean you'd never be lonely…I think if...I was younger, I wouldn't feel insecure." The participants had lost their life partner, which brought concern for the future. One participant said: "I looked after him now I have no one to look after me, you know." The participants were facing an uncertain future of being alone: "...you're questioning the unknown of what's ahead, you know, what your life's going to be now, and um, striking out alone, it's a whole new adjustment."

Each of the participants was interacting with family, friends, and neighbours which greatly affected their experience of bereavement. In most situations, these relationships were very important sources of support through difficult times, especially when intra-personal concerns were overwhelming. One participant said: "I've got good support, I've got wonderful neighbors." Another said: "I felt that I had a good support system and people haven't really allowed me to get down." One participant wrote about her daughter's support: "Without her calls at least once a day-and all the support from everyone I don't know how I'd have got through...Family so important through bad times!"

However, difficulty in relationships also greatly affected bereavement. If families were not getting along, the strain was almost unbearable. One participant said:

"I think probably um…that's probably the biggest concern that I have right now is…is

to be a family." A participant described feeling rejected by previous friends. She said:

"Yeah, people reject me. See like they have never known me, you know? You, you

wonder why, you know because that's the time that you really need them the most."

Another said: "sometimes I feel that people don't want to listen to me." Inter-personal

relationships were very important to the participants in the study, and when they became

sources of stress it added to the pain and suffering they were already experiencing. A

participant was upset about family members who were not close before the death of her

husband, but now were calling about issues in the will. She said: "Maybe they don't

realize how what they were doing was affecting me. I don't think they even gave it a

thought." Each of the participant's friends and family members was also bereaved and

some were recovering from caregiving. One said: "The first two times he seen me alone

he wept." One participant, who was having a very difficult time during bereavement,

felt she needed to give her children time off, since they had frequently traveled home to

help with caregiving during her spouse's illness. But not seeing her family meant a great

deal of loneliness for her and she was having a very difficult time during bereavement.

Community/Societal Context: "Just Need to Find my Way"

The overall theme of the community/societal context was described by the

participants in this study as "just need to find my way". It was a difficult adjustment

after many years as a married person in the community. One participant described it as:

"really adjusting to being a widow and that's the, that's the word right there, I know that

I am a widow, and I need to, I just need to find my way." Within this theme, the

subthemes were a loss of identity and assuming a new role as a widow, moving out of

their homes, feeling pressured to get over their difficult emotions, financial concerns, dealing with difficult seasons in the year, and relying on the support of the community and the health care system.

Their new roles as widows meant a loss of identity in their social world and the general community, as one participant described it: "...loss of identity, you know, you're…I was (spouse's name)'s wife." The word "widow" was hard to say. One participant wrote in her diary as she acknowledged to herself the impact of her husband's death: "I am now a widow. My life has changed." She was not sure of her ability to become "a new me".

Having to move from their homes was on the minds of many of the participants. Two of the participants had been forced to move within a few months of the death of their spouse, which was very difficult. One said: "I felt like I lost everything at once." Several of the others were planning to move from homes with yards they were unable to care for. One said: "I mean moving to a new place and then having…having no friends," and "But this moving part that's on my mind a lot." All of them were thinking about moving, which meant more losses such as leaving memories, a lifestyle, and neighbours. One said: "this is my home, but, for how long? You know, how long am I going to be able to keep it up?"

Many of the participant's expressed concern about the pressure they felt from others around them to move on and get over the difficulties they were experiencing and get on with their lives. One said: "I thought OK, where is it written that I have to get rid of his stuff?" A participant said: "…people say 'Well she's not getting over that very well. She's not healing very well. She's still has all his stuff', and I'm like…well you

know what…it's none of their business." One participant said: "People sometimes say, 'Don't you think you're starting to feel sorry for yourself', but I said, 'that's about all I can think about is how life use to be and it's so different now". One participant said: "I've been told to move on." The challenge of having to face societal pressures made the process of bereavement more difficult. A participant described it this way: "I think that community and society kind of expects you to get on with life, and so, and everybody does that at a different time."

For some of the participants, losing a spouse meant losing financial security. Most of the participants were feeling comfortable financially, but two were actively looking for work, and two others were employed. As one participant said: "And I do have to go to work, financially, I mean, yeah, there may be funds there but you know…I do have to live."

All of the participants described going through difficult seasons of the year such as Christmas, Easter, and Valentine's Day, without their spouse. One participant said: "if it was me, I wouldn't even bother with Christmas." The seasons brought societal expectations of happy times with family and friends, but for the participants it meant facing each special occasion and holiday without their spouse. As one participant said: "there's so many memories."

The support of the community and the health care system was very important. One said: "The thing I'm most thankful for, a family doctor that's so understanding." Receiving information about bereavement in the mail was helpful. The participants were invited to services of remembering. One described the services this way: "...to see the light, through the darkness to help the pain go away." A participant wrote: "Hope today

is knowing that the community shares in my loss, and I am grateful for the support, holding a remembrance service, helping all of us who lost loved ones this past year 'get past Christmas' this year and have hope in the future." One said: "I wondered if I was losing my marbles, because of the, you know, different things, mostly dreams, and I find that other people have the same thing happen to them, so that's normal."

The psycho-social context of the participants in this study was categorized into intrapersonal, interpersonal, and community/societal contexts, as illustrated in Figure 1. Each of the circles is interconnected and simultaneously affects the experience of bereavement, for example supportive relationships eased the loneliness during bereavement but difficult relationships and societal expectations added to the intrapersonal challenges they were experiencing. The participants in this study were experiencing unique and challenging circumstances in all aspects including loneliness, physical and emotional concerns, difficult relationships, and a loss of identity that directly affected the processes of bereavement.

<center>Discussion</center>

Some of the findings of this study are similar to findings in other research studies with bereaved caregivers of palliative cancer patients. However, the diagram depicting the overall psycho-social context of a specific group of participants is unique in the literature. Although researchers acknowledge the central role of the social/interpersonal setting of bereavement and interaction with others (Stroebe et al., 2001), the exploration of social context is often neglected in bereavement research.

The participants described their experience within the intrapersonal context to include loneliness, pain, emptiness, feeling exhausted from caregiving, and facing

physical and emotional challenges, while losing a partner and caregiver. Bereavement maladjustment has been linked to a difficult caregiving experience in a study of 111 home-based caregivers. Those at greatest risk were older women (61 years and older) who lost a spouse (Ferrario et al., 2004). High symptom severity of the family member during caregiving predicted difficulties in bereavement in a study of 96 bereaved caregivers (Grande et al., 2004). Qualitative studies with bereaved palliative caregivers describe exhaustion from caregiving (Jacob, 1996) and lingering mental pictures of the suffering of the dying patient during bereavement (Koop & Strang, 2003). Further research is needed to examine the interconnections between the caregiving experience and the intrapersonal aspects of bereavement, especially for at-risk populations such as older women.

Physical health was a concern in bereavement for the participants in this study. Increasing age brought more health challenges, for example a participant who was 79 years old died during the study. Difficulty sleeping, the loss of a caregiver, and recovering from the exhaustion of caregiving were also physical concerns. This is similar to a study of 1858 bereaved carers of persons who died of cancer, 25% rated their health as poor or fair at ten months post-bereavement (Fakhoury, McCarthy, & Addington-Hall, 1997). Increasing age predicted poorer physical health in bereavement in a correlational study of 151 family caregivers (Brazil, Bedard, & Willison, 2002). Sleep disturbances affected the tasks of bereavement in a study of nine caregivers, bereaved less than six months (Carter, 2005). The Changing Lives of Older Couples [CLOC] study with 1523 older spouses described the social regulation of health, meaning the loss of a spouse that reminded and encouraged you to take care of yourself

was detrimental to ongoing physical health during bereavement (Williams, 2004).

Previous research provides support for the current findings, although more research is

needed to identify appropriate, effective, and efficient policies and programs of support

for bereaved caregivers, to specifically address their physical health concerns.

All of the participants described the emotional difficulties they experienced

during bereavement. This is similar to the intense emotional distress reported by

bereaved caregivers (Grbich et al., 2001). Similarly in research with 45 bereaved

palliative caregivers, 22% were not coping well, and 42% described loneliness,

exhaustion, sadness, worry, and anxiety, at six months post-bereavement (Hudson,

2006). The overwhelming number of losses experienced by the participants, including

loss of a caregiver and partner, were not reported by Hudson.

The interpersonal context of bereavement for the participants in this study

involved "striking out alone", or beginning a new life as a single person. The

participants were dependent on the support of others while dealing with difficult,

stressful relationships in their lives. Previous research supports these findings. Relatives

and friends played an important role in the recovery from bereavement (Brazil et al.,

2003), although in a qualitative study of 15 home-based caregivers, increased conflicts

in relationships interfered with a family's ability to support each other (Koop & Strang,

2003). Similarly, the complexity of social support, which was at times absent or

reluctant, emerged in a mixed methods study of 20 older widows (Scott et al., 2007).

Results from the CLOC prospective study of 1532 older widowed individuals, revealed

the level of social support was not associated with distress levels or recovery from

bereavement, although it was predictive of levels of depression (Stroebe, Zech, Stroebe,

& Abakoumkin, 2005), different than the current study, where participants described the importance of support during bereavement. Further research is needed to examine the meaning and processes of social support in bereavement for unique populations such as older women.

The community/societal aspects of social context for the participants were summarized, as "just need to find my way". The participants experienced a loss of identity in their community, while being expected to move on with their bereavement. Difficult times of the year, financial concerns, and relying on support of the community and health care system, were aspects of the social context of bereavement. Very little research has been done to examine bereavement within a community context. One study reported financial concerns expressed by 45% of 124 bereaved caregivers interviewed at 3 months post-bereavement (Wyatt et al., 1999). Receiving support through palliative care services was described as helping the bereavement experience in a study with 105 bereaved caregivers (Reid, Field, Payne, & Relf, 2006). The participants in this study were receiving support from the local health region through mailings and offering a support group, although other research with bereaved caregivers described a need for support (Jansma, Schure, & Meyboom de Jong, 2005). The role of the community and society in the social context of bereavement requires further exploration.

<div align="center">Factors Influencing the Study Findings</div>

The context of the study, the methodology, and the sample had an impact on the findings of this study. The sample was from a small Canadian city, with resources available to support caregivers, which they were receiving both during caregiving and into bereavement. The women in this study were Caucasian. The methodology allowed

the participants to describe their experience, tell their stories, and provide insight from their own perspectives. The sample was a relatively homogenous sample of older women who were bereaved following caregiving for a spouse with cancer in western Canada, although there was variation in their ages, length of caregiving, and support systems. People from different ethnic and religious groups, socioeconomic status, cultural groups, gender, or geographic locations would describe a different context of bereavement. The participants in this study were willing to meet with a nurse researcher. Those who were having a more difficult time, either physically or emotionally, or not interested in participating, were not a part of the study, which may have affected the results. As well older women have unique concerns including many secondary losses and physical changes which may impact the study results. The findings of this study need to be interpreted considering these factors.

Implications for Practice and Research

The results of this exploratory, descriptive study may be used to guide practice and plan ongoing research with people going through bereavement. The women in this study were experiencing a wide range of concerns and experiences within their intrapersonal, interpersonal and community/societal social contexts. The many secondary losses as a result of caregiving and then losing a spouse must be considered when services are being accessed or programs of support are being planned. Support is very important, both from family, friends, and neighbours, but also from the community and the health care system. However, there will be relationships that also cause stress and difficulties during bereavement. Although there are similarities in the processes of bereavement, the psycho-social context of each individual will determine how they are

affected by bereavement and what supports are needed. Health care professionals can offer understanding, reassurance, and support and monitor physical and emotional health while encouraging each person to find their own way through bereavement. It is important to assess the individual impact of bereavement from the perspective of each of these domains, to most effectively provide intervention and support, with the goal of promoting health and positive outcomes during this difficult time of transition.

The diagram (Figure 1) of the results of this study may provide a helpful explanation for the equivocal results of other studies with bereaved people since the experience of bereavement is affected by many variables that are subject to frequent change. Ongoing research is needed with younger women who are bereaved, other cultural groups and geographic locations in order to develop and evaluate interventions, supports, and programs of care, possibly based on the diagram of the psycho-social context of bereavement.

Conclusion

Support for family caregivers is mandated by international palliative care guidelines, to extend into the time of bereavement (World Health Organization, 2002), with the specific goal of encouraging a successful transition and reintegration into society after the caregiving experience and/or the loss of a family member (Ferris *et al.*, 2002). However, very little is known about the needs and experience of the bereaved family caregiver or how best to provide evidence-based supports that will promote positive outcomes during bereavement. Exploring and understanding the psycho-social context for an older woman who is bereaved following caregiving for a spouse with terminal cancer may provide an opportunity for effective and compassionate care.

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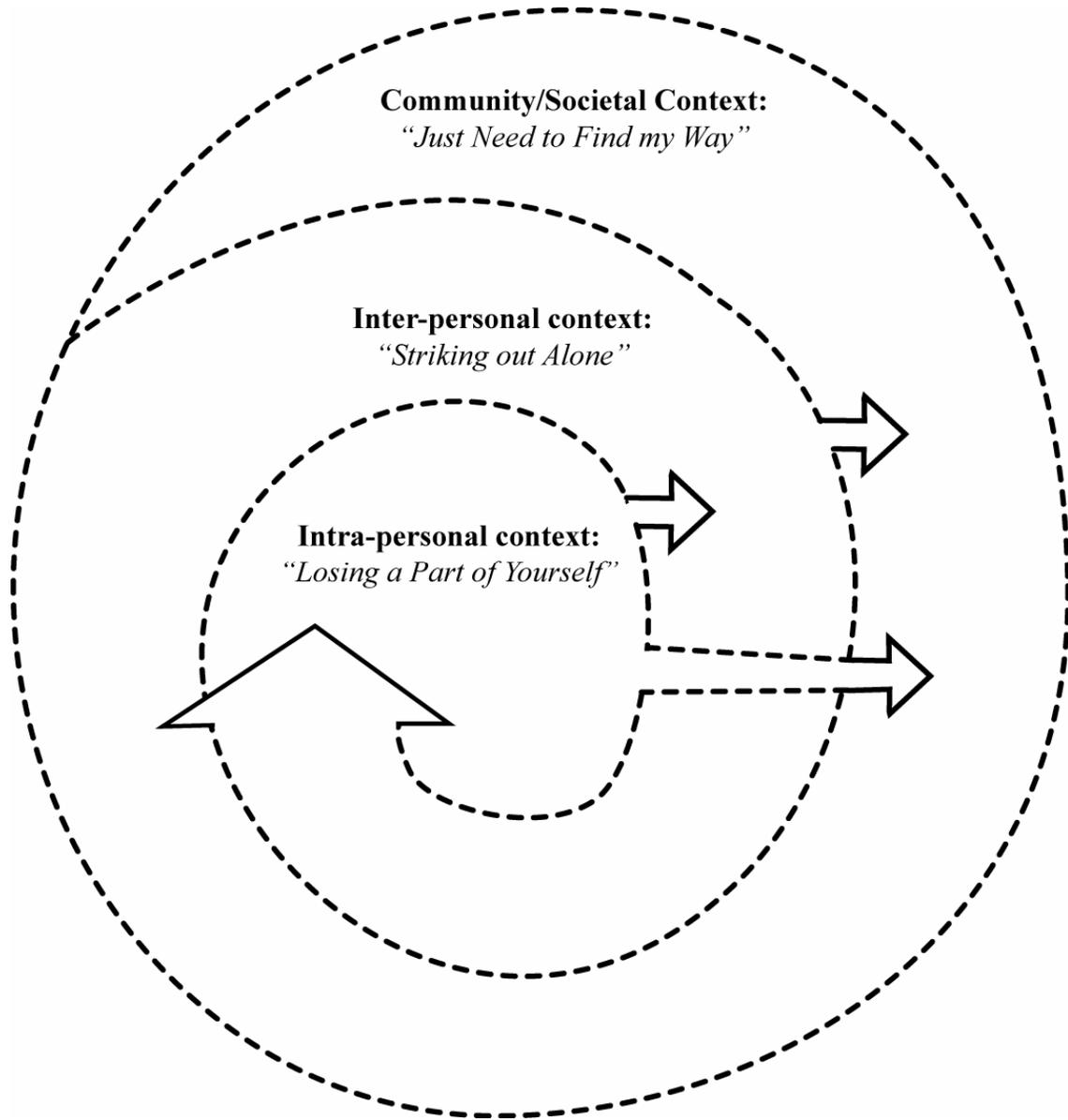
    15(1), 13-25.

Table 1

Demographic Characteristics of the Thirteen Participants

Characteristics	Number
Age:	
60-69 years	7
70-79 years	6
Ethnicity:	
Caucasian	13
Religious Preference:	
Protestant	7
None	3
Catholic	3
Years of Education Completed:	
8-12 years:	7
13-16 years:	6
Primary Diagnosis of Patient:	
Lung Cancer	3
Unsure of primary ca	3
Lymphoma:	2
Pancreatic Cancer	2
Prostate Cancer	2
Kidney cancer	1
Length of Caregiving:	
1-3 months	3
4-6 months	4
7-12 months	3
More than 12 months	3
Main Support System:	
Children close by	6
Children out of town	3
Friends	2
Other relatives	2
Months Since Death of the Patient:	
3-6 months	3
7-9 months	7
10-13 months	3

Source: Author

Figure 1: The Psycho-social context of Bereavement

Community/Societal Context:
"Just Need to Find my Way"

Inter-personal context:
"Striking out Alone"

Intra-personal context:
"Losing a Part of Yourself"

Source: Author

Appendix A Ethics Approval University of Saskatchewan

UNIVERSITY OF SASKATCHEWAN

Behavioural Research Ethics Board (Beh-REB)

Certificate of Approval

PRINCIPAL INVESTIGATOR	DEPARTMENT	Beh #
Wendy D. Duggleby	Nursing	06-211

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT
University of Saskatchewan

Saskatoon   SK

SUB-INVESTIGATOR(S)
Lesley Degner

Lorraine Holtslander

SPONSORING AGENCIES
UNFUNDED

TITLE
The Experience of Hope in Bereaved Caregivers of Palliative Care Patients

APPROVAL DATE	EXPIRY DATE
25-Aug-2006	01-Aug-2011

| APPROVAL OF	APPROVED ON
Will now recruit patients through Eleanor Edwards at the W. A. Edwards Family Centre, Saskatoon Funeral Home.	27-Feb-2007

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

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

ONGOING REVIEW REQUIREMENTS
In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.usask.ca/research/ethics_review/
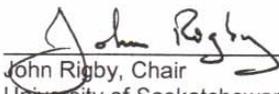
John Rigby, Chair
University of Saskatchewan
Behavioural Research Ethics Board
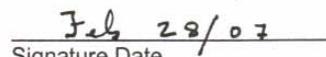
Feb 28/07
Signature Date

Please send all correspondence to:
Ethics Office
University of Saskatchewan
Room 306 Kirk Hall, 117 Science Place
Saskatoon SK S7N 5C8
Telephone: (306) 966-2084   Fax: (306) 966-2069

Appendix B Operational Approval from the Saskatoon Health Region

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<table>
<tr>
<td>
Saskatoon
Health
Region
</td>
<td>
Research Services Unit
Strategic Health Information & Planning Services (SHIPS)
Joanne Franko, Manager
Suite 300 Saskatoon Square
410 22nd St E
Saskatoon, SK   S7K 5T6
Phone: 306.655.3356 Fax: 306.655.3373
</td>
</tr>
</table>

DATE: October 10, 2006

TO: Dr. Wendy Duggleby, College of Nursing, U of S

FROM: Joanne Franko
             Manager, Research Services Unit

RE: **RESEARCH PROJECT ETHICS COMMITTEE (EC)#: B2006-211**
             PROJECT NAME: The Experience of Hope in Bereaved Caregivers of Palliative
             Care Patients
             PROTOCOL #: N/A

Saskatoon Health Region is pleased to provide you with operational approval of the above-mentioned research project.

Please advise me when the data collection phase of the research project is completed. I would also appreciate receiving a summary of the results for this research project. As well, any publications or presentations that result from this research should include a statement acknowledging the assistance of Saskatoon Health Region.

I would like to wish you every success with your project. If you have any questions, please contact our office at 655-3351.

Yours truly,
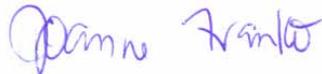
Joanne Franko, M.Sc.
Manager, Research Services Unit

cc: Meredith Wild, MON, Palliative Care, SPH