

The Bereavement Experiences of
Family Caregivers with Uncomplicated Grief

by

Moira Cairns
B.A., University of Victoria, 1968

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This study explored the experiences of bereaved family caregivers (FCGs) with uncomplicated grief in hospice palliative care and what they found helpful and challenging in their adjustment to the loss of the person for whom they were caring. The cumulative effects of both caregiving and bereavement can be detrimental to FCGs' physical, social, and mental well-being. Many FCGs with uncomplicated or normal grief ask for assistance in bereavement. Yet, in the bereavement care literature, there is uncertainty about what may be beneficial to them and how best to support them. An interpretive descriptive design was used for this study of eleven bereaved FCGs with uncomplicated grief. The FCGs included five daughters, 5 spouses (2 wives, 2 husbands, 1 same-sex partner), and one sibling who had cared for a dying family member and who ranged in age from 23 to 76 years. All participants resided in the Vancouver Island Health Authority – South Island region. Data were collected through eleven in-depth interviews and one focus group. Data were analyzed using inductive analysis. The FCGs reported that the impact of loss was experienced as a magnitude of changes in their everyday lives, the loss of the connection with the cared-for person, and changes within themselves. They also reported a need for a safe community in which to grieve where they had quality relationships and/or shared common experiences of loss with others.

Finally, the FCGs reported active engagement in their adjustment in bereavement that included such strategies as remembering the person who died, striving for balance, and awareness of personal growth. The findings from this study have the potential to assist health care and other professionals to understand the bereavement experiences of FCGs in hospice palliative care and to inform bereavement care for FCGs with uncomplicated grief.

Table of Contents

Supervisory Committee.....	iii
Abstract.....	iv
Table of Contents.....	v
List of Tables.....	vii
Acknowledgements.....	viii
Dedication.....	ix
CHAPTER 1	
Introduction.....	1
<i>Background to the Problem</i>	2
<i>Statement of the Problem</i>	5
<i>Purpose of the Study</i>	6
<i>Definition of Terms</i>	6
<i>Researcher Assumptions And Beliefs</i>	7
<i>Significance of the Study</i>	7
CHAPTER 2	
Review of Existing Knowledge	9
<i>Family Caregivers and Bereavement</i>	10
<i>Bereavement Adjustment</i>	13
<i>Impact of Bereavement</i>	14
<i>Historical Influences on Theory and Research</i>	15
<i>Current Models of Bereavement Coping and Adjustment</i>	19
<i>Influences on Bereavement Outcomes</i>	22
<i>Bereavement Care</i>	29
CHAPTER 3	
<i>Methods</i>	36
<i>Research Design</i>	36
<i>Participants</i>	37
<i>Primary Sample</i>	37
<i>Participant recruitment</i>	37
<i>Inclusion/exclusion criteria</i>	38
<i>Description of participants</i>	39
<i>Secondary Sample</i>	40
<i>Data Collection Procedure</i>	42
<i>Data Analysis</i>	43
<i>Rigor</i>	45
<i>Ethical and Human Rights Considerations</i>	48
<i>Informed Consent</i>	48
<i>Confidentiality</i>	49
<i>Vulnerability of the Population</i>	49
<i>Limitations of the Study</i>	50
<i>Potential Significance of the Study</i>	50
CHAPTER 4	
Findings.....	52
<i>Family Caregivers' Experiences of the Impact of Loss</i>	53
<i>Magnitude of Changes in the Family Caregiver's Life</i>	54

<i>Loss of Connection with the Person who Died</i>	55
<i>Missing the person who died.</i>	56
<i>Personal Changes for the Family Caregiver</i>	60
<i>Struggling with shifts in identity.</i>	60
<i>Facing unfamiliar responsibilities, choices, and decisions.</i>	62
<i>Needing a Safe Community in which to Grieve</i>	64
<i>The Challenges of a Supportive Community in Bereavement</i>	65
<i>Wanting to be accepted.</i>	65
<i>Misguided offers of support.</i>	66
<i>Encountering social expectations about grief and bereavement.</i>	68
<i>Components of a Safe Community in which to Grieve</i>	70
<i>Feeling validated and justified.</i>	70
<i>The quality of the relationships.</i>	72
<i>Sharing a common experience with another.</i>	73
<i>Active Engagement in Adjusting</i>	75
<i>Remembering the Person who Died</i>	76
<i>Recognizing A Different Connection with the Person who Died</i>	78
<i>Striving for Balance</i>	81
<i>Appreciating the Good in Life</i>	85
<i>Awareness of Personal Growth</i>	87
<i>Summary of Findings</i>	90
CHAPTER 5	
Discussion.....	93
<i>Models of Bereavement and Adjustment</i>	94
<i>FCGs' Experiences of the Impact of Loss</i>	95
<i>Needing A Safe Community In Which To Grieve</i>	97
<i>Active Engagement in Adjusting</i>	101
<i>Caveats and Limitations of the Study</i>	107
<i>Implications for Practice and Policy</i>	108
<i>Directions for Further Research</i>	112
<i>Summary of the Significance of the Study</i>	114
Bibliography.....	117
Appendix A - Definitions.....	123
Appendix B – Letters of Invitation.....	126
Appendix C – Demographic Information Form.....	131
Appendix D – Interview Guide.....	136
Appendix E – Informed Consent Forms.....	139

List of Tables

Table 1: Demographic Information for Family Caregivers and Persons who Died

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Dedication

In memory of

my darling big brother

Ian Anguish 1946 – 2006

my step-mother-in-law

Meg Lindsay 1928 – 2008

my own Mum

Jean Anguish 1921 – 2008

with appreciation for all they taught me

about caregiving and bereavement.

CHAPTER 1

Introduction

As changes in the health care system continue, family members are providing more care and carrying out a wider range of tasks to attend to patients with terminal illnesses at home. Caring for a dying person at home is a considerable undertaking with potential to negatively affect family caregivers' (FCGs') mental and physical health. Family caregivers' experiences of caregiving can have a substantial impact on the course and outcome of their bereavement (Koop & Strang, 2003; Stajduhar, 2003). Many FCGs, including those with uncomplicated or normal grief, are potentially vulnerable to difficulty with adjustment in bereavement.

More than 259,000 Canadians die each year - almost three quarters of them from illnesses of the circulatory or respiratory systems or from various forms of cancer (CHPCA, 2008). Each death may affect the immediate well being of five other people, meaning that 1.25 million Canadians are bereaved each year (CHPCA, 2008). The World Health Organization (WHO), the Canadian Hospice Palliative Care Association (CHPCA), and other palliative care organizations world-wide state that bereavement care is an integral aspect of palliative end-of-life services and that FCGs should be supported after the death of the patient (WHO, 2004; CHPCA, 2003). Many bereaved FCGs request assistance and support from health care professionals, especially those health care professionals who were present during the time of caregiving for the dying person. The majority of FCGs who seek support will have normal or uncomplicated grief. There is little research on what is helpful and what is challenging for these bereaved FCGs to guide health care professionals' responses to them.

Background to the Problem

Family caregivers' adjustment in bereavement is affected by two major life stressors: first, caregiving for a dying family member and, second, the loss of a family member or significant person. The complex experiences of caregiving and bereavement conjoin to make FCGs potentially vulnerable to difficulty in adjusting in bereavement. Caregiving for a seriously ill person is a potential burden as it can be exhausting, both physically and emotionally. It also can be life affirming and a gift gladly given but FCGs take on an enormous responsibility in caring for a family member who is dying (Koop & Strang, 2003; Stajduhar; 2003). Family caregivers often begin their bereavement depleted by the caregiving experience (Addington-Hall & Karlsen, 2000).

Although caregiving ends with the death of the patient, FCGs go on to face the challenges of adjusting to the loss of a family member or significant other and, for some, also adjusting to the loss of the caregiving role. Losing a family member is a painful experience and grief can include intense suffering. Adjustment in bereavement goes on for an extended period. The cumulative effects of both caregiving and bereavement can be detrimental to FCGs' physical, social, and mental well-being (Bernard & Guarnaccia, 2003). Although there is a growing body of literature about family caregiving in palliative care, little of it focuses on the bereavement experiences of FCGs or on what may be helpful and challenging in their adjustment in bereavement.

The current state of knowledge about FCGs and bereavement includes descriptions of the potential burdens of caregiving and bereavement. Many FCGs provide care 7 days a week over a period of weeks and months (Bramwell, MacKenzie, Laschinger, & Cameron, 1995). It has been reported that FCGs provide an average of 10.8 hours of direct care and 8.9

hours of companionship each day (Wyatt, Friedman, Given, & Given, 1999). Approximately one half of caregivers report chronic illnesses of their own (Strang, Koop, & Peden, 2002). Up to one third of palliative caregivers exhibit symptoms of depression and other mental and physical problems that may affect their long-term health (Kissane, Bloch, Burns, McKenzie, & Posterino, 1994; Martens & Davies, 1990). It is known that FCGs may neglect their own health as they focus on that of the dying person (Payne, Smith, & Dean, 1999).

When the patient dies, the end of caregiving may bring some relief to family members who have been providing care (Schulz, Newsom, Fleissner, Decamp, and Nieboer, 1997). However, the patient's death may also worsen the depletion of personal resources and strain from caregiving experienced by FCGs (Bernard & Guarnaccia, 2003). Painful emotions experienced in caring for a dying family member worsen after the death (Grbich, Parker, & Maddocks, 2001). Family caregivers are potentially vulnerable to difficulty in bereavement compared to other relatives of the patient (Bodnar & Kiecolt-Glaser, 1994). Although there is a growing body of research with bereaved FCGs, some of which focuses on particular issues in bereavement, there is a dearth of research about the bereavement experiences and adjustment of FCGs with uncomplicated grief.

Theoretical models of bereavement and bereavement adjustment inform the current state of knowledge about bereavement adjustment. Stroebe and Schut (1999) proposed the dual process model of coping in bereavement that includes grief processes and restoration processes. Grief processes address the emotional, social, and psychological impact of the loss while restoration processes address the changes that come with the loss of a significant person. This model has had an impact on recent directions in bereavement adjustment research. Research has moved away from a focus on the detrimental effects of bereavement

toward a greater interest in positive influences on bereavement adjustment. Current research includes numerous quantitative studies on factors, such as resilience, self-efficacy, or positive emotions, that may influence bereavement outcomes, such as depression or emotional distress (Benight, Flores, & Tashiro, 2001; Bonnano, Moskowitz, Papa, & Folkman, 2005; Ong, Bergeman, & Bisconti, 2004). Other research endeavours have been aimed at providing evidence for the success of interventions for people with complicated or traumatic grief (Jordan & Neimeyer, 2003; Zhang, El-Jawahri, & Prigerson, 2006). Little research, however, has focussed on what promotes adjustment for people with uncomplicated or normal grief or for FCGs, in particular. Health care professionals in palliative end-of-life care are in need of this knowledge in order to provide appropriate care to these FCGs.

In terms of the provision of bereavement care, the current state of knowledge includes a discourse around complicated and uncomplicated grief, who is in need of care and support, and what that care should be. Normal or *uncomplicated grief* can include responses such as depression, despair, anger, guilt, fatigue, crying, social withdrawal, low self-esteem, problems with memory and concentration, sleep disturbances, and susceptibility to disease (Stroebe, Hansson, Stroebe, & Schut, 2001). It can also include adaptive challenges such as changed social and intimate relationships, practical functioning, and building a new identity (Chentsova-Dutton & Zisook, 2005). *Complicated grief* involves more intrusive and distressing symptoms that persist beyond 6 months plus marked and persistent symptoms of traumatization (Prigerson & Jacobs, 2001). It has been suggested that bereaved individuals with uncomplicated grief will have quite different bereavement support needs than those with complicated grief (Walsh-Burke, 2000). While it is known that bereaved people with complicated grief benefit from psychotherapeutic intervention such as individual

psychotherapy or psychiatric care (Schut, Stroebe, van den Bout, & Terheggen, 2001), it is unclear what should be done for those bereaved individuals with uncomplicated grief (Center for Advancement of Health, 2004; Schut et al., 2001). Bereavement care for FCGs with uncomplicated grief has received relatively little attention, perhaps because it is assumed that most bereaved individuals manage with their natural supports and that bereavement care interventions for persons with uncomplicated grief are unnecessary and unproductive (Center for the Advancement of Health, 2004). The majority of bereaved FCGs will experience uncomplicated grief and, as they continue to seek help and support in adjusting in bereavement, it is important for health care professionals to have knowledge to guide their responses and the provision of care.

Statement of the Problem

In recent years, the number of FCGs caring for a dying person at home has increased and is likely to continue to increase due to aging of the Canadian population (CHPCA, 2008). Many of these FCGs ask health care professionals for assistance in bereavement. The demands and stresses of caregiving can deplete FCGs' physical and psychological resources. Even though the majority of FCGs will experience normal or uncomplicated grief, that experience often includes distressing emotional, social, and psychological responses to the death of a significant person and to the changes that follow. As distress is common in the early months of bereavement, it is uncertain who may develop complicated grief (Schuchter & Zisook, 1993). Early appropriate response from health care professionals may prevent complications and promote healthy adjustment in bereavement for FCGs. In the present uncertainty over what FCGs with uncomplicated grief find helpful and how best to support them, it is important to have research that illuminates the experiences of these FCGs and

what may promote their adjustment in bereavement in order to provide appropriate bereavement care to this group.

Purpose of the Study

The overall aim of this study was to expand on existing literature to gain better insight into the bereavement experiences of FCGs with uncomplicated grief. The research question that guided this study was: In the context of hospice palliative care, what do bereaved FCGs with uncomplicated grief identify as helpful and challenging in their adjustment to the loss of the person for whom they were caring? The specific objectives of this research were to: (1) describe the experiences of bereaved FCGs with uncomplicated grief; (2) describe what bereaved FCGs find helpful and what they find challenging in adjusting to the loss of a significant other; and (3) to identify factors or influences that promote adjustment in bereavement for FCGs.

Definition of Terms

For the purposes of this study, the following terms were defined:

Uncomplicated grief: The diverse natural reactions, such as psychological, physical, and social reactions, to the loss of a significant person characterized by both suffering and growth (Stroebe et al., 2001). These reactions are considered normal. Uncomplicated grief is an exclusionary term as it is applied to anyone *not* assessed as having complicated grief and includes a broad range of grief responses. Criteria for complicated grief include that sufferers experience the following: (1) bereavement by death; (2) an intrusive and a distressing set of core symptoms which include yearning, longing for, and searching, that persist beyond 6 months; (3) four or more marked and persistent symptoms of traumatization such as, avoiding reminders of the person who died, purposelessness, feelings of futility, difficulty

imagining life without the person who died, numbness, detachment, feeling stunned/dazed/shocked, feeling that life is empty or meaningless, sense that a part of oneself has died, disbelief, excessive anger related to the death, and symptoms similar to those suffered by the person who died (Prigerson & Jacobs, 2001).

Family Caregiver: anyone (related or not) who provides care for someone who is seriously ill and is not paid to do so. *Care:* anything you do for the person because he or she has a serious illness, such as, direct physical care for the ill person, arranging and attending appointments, transportation, and increased household chores.

Bereavement: is not only the loss of a significant person but also the period of transition for the bereaved individual following that person's death (Stroebe & Schut, 1999).

Adjustment in bereavement: is the process and outcome of the overall efforts of the individual to process loss and change precipitated by the death (Adapted from Stanton, Collins, & Sworowski, 2001).

Researcher Assumptions And Beliefs

As an experienced bereavement counsellor in palliative care, I bring not only clinical knowledge to this inquiry but also certain assumptions and beliefs. I bring the assumptions that many bereaved people with uncomplicated grief suffer and that FCGs with uncomplicated grief should be able to access support from the health care system for their distress. I believe that there is much to be learned from FCGs with uncomplicated grief about healthy adjustment in bereavement.

Significance of the Study

The majority of bereaved FCGs have uncomplicated grief and many of them ask for help and support from health care professionals. Little is currently known about what is

helpful or challenging for those with uncomplicated grief in adjusting in bereavement. FCGs are potentially vulnerable to difficulties in bereavement because of the combined effects of the stresses of caregiving and of bereavement. Family caregivers are among those who request bereavement care, yet there is little empirical knowledge to guide health care professionals in responding to the needs of this group.

The insights from this study may assist health care professionals to understand FCGs' experiences after the cared-for person dies and provide potential strategies that support FCGs in their adjustment in bereavement. The knowledge gained from this study may help to determine effective bereavement care to reduce the physical, mental, and social health risks associated with caregiving and bereavement. Family caregivers themselves may benefit from an understanding of the experiences of other people in similar circumstances and knowledge of what has helped them to adjust.

This study makes a contribution to the caregiving and bereavement literature in describing FCGs' bereavement experiences and the effects of these experiences on adjustment to the loss of a significant other. Knowledge gained from this study may answer questions about the needs of those with uncomplicated grief. Likewise, this study adds to the understanding of influences on bereavement adjustment through suggesting what may be helpful or challenging to FCGs as they adjust to their loss and to the changes in their lives.

CHAPTER 2

Review of Existing Knowledge

Several areas of research literature were reviewed to highlight current knowledge related to the research question and purposes of this study. First, research knowledge relating to bereaved FCGs was examined to demonstrate the impact of caregiving on FCGs in hospice palliative care and occurrences during caregiving that influence bereavement. Then, knowledge related to bereavement adjustment was reviewed. Within this area, models of bereavement and adjustment were examined. Also, the current evidence on the influences on adjustment in bereavement was appraised in relation to what bereaved FCGs may find helpful and challenging following the death of the person for whom they were caring. Finally, the state of evidence relating to bereavement care was reviewed as it pertains to FCGs and persons with complicated and uncomplicated grief. Gaps in the current knowledge in these areas were identified as they help to frame the questions guiding this study.

I conducted the literature review by searching various sources. I did on-line searches within CINAHL, Medline, PsychInfo, and Social Sciences Index using search terms including bereavement or grief, in combination with one or more of the following: family caregiver, adjustment, care, intervention, uncomplicated grief, hospice, and palliative care. I also searched the NET/ NCIC RefWorks database for articles concerning family caregivers and bereavement. These searches produced a number of articles relevant to my study and their reference lists from these articles provided further articles of interest. Several journals, including the Hospice Journal, the European Journal of Palliative Care, and the American Journal of Hospice and Palliative Medicine, were

hand-searched for the years 2001 to 2006. I also used relevant edited volumes and text books as source materials.

Family Caregivers and Bereavement

There is a rich and growing body of knowledge on family caregiving and FCGs in palliative care. The literature includes descriptions of FCGs' experiences of caring for a dying person and the effects these can have on FCGs during caregiving. There is also a smaller body of knowledge on the effects of caregiving experiences on FCGs in their bereavement.

As many hospice palliative care patients wish to be cared for at home as long as possible, FCGs play a vital role in hospice palliative care (CHPCA, 2008; Senate Subcommittee on End of Life Care, 2000). Moreover, changes in the health care system toward more care in general being given in the home place increased demands on FCGs (Chappell, 1993; CHPCA, 2008; Stajduhar, 2003). The impact of these demands includes physical burdens and health strains on FCGs. The physical burdens of caregiving can be substantial as many FCGs provide care seven days a week, for weeks and months (Bramwell et al., 1995). Wyatt and colleagues' (1999) descriptive study of 124 bereaved FCGs found that they provided an average of 10.8 hours of direct care and 8.9 hours of companionship each day. Approximately one half of FCGs reported chronic illnesses of their own (Strang, Koop, & Peden, 2002). Close to a third of FCGs engaged in palliative caregiving experience symptoms of depression and other psychological and physical problems that have the potential to affect their long-term health (Kissane et al., 1994; Martens & Davies, 1990). It is known that FCGs may neglect their own health as they focus on the health of the dying person (Zapart, Kenny, Hall, Servis, & Wiley, 2007). Approximately one third of families in

hospice palliative care experienced moderate disruptions in family functioning, such as cohesiveness, expressiveness, and conflict resolution; a further one fifth experienced severe disruptions (Kissane et al., 2003). These challenging factors conjoin to leave FCGs potentially weakened by poor health, burden, and neglect during caregiving as they face the additional challenge of bereavement following the death of the cared-for person (Addington-Hall & Karlsen, 2000). It is important for health care professionals, in their interactions with bereaved FCGs, to have an understanding of the context of caregiving and its relationship to FCGs' vulnerability to difficulties in bereavement.

Both positive and negative experiences in caregiving can have consequences for FCGs in their adjustment in bereavement. For example, experiencing negative consequences of caregiving, such as increased depression and poorer health, is related to increased psychological symptoms (Chentsova-Dutton, Shucter, Hutchin, Strause, Burns, Dunn, et al., 2002) and poorer adjustment in bereavement (Brazil et al., 2003). In a survey of 151 bereaved FCGs, the reporting of negative consequences of caregiving was a predictor of poorer recovery in bereavement (Brazil et al., 2003). Bodnar and Kiecolt-Glaser (1994) found that the multiple sacrifices of caregiving accelerated negative changes in the social network that were difficult to redress in bereavement. Decrements to the social network and to mental health carried over into bereavement and were not overcome within three years (Bodnar & Kiecolt-Glaser, 1994). In Grbich and her colleagues' (2001) qualitative study of 20 FCGs, all of the FCGs reported that painful emotions experienced in caring for their dying family member worsened after the death. The level of caregiver involvement in patient care is positively related to depression levels in bereavement (Boerner, Schulz, & Horowitz, 2004; Mullan, 1992). Both Mullan (1992) and Boerner and colleagues (2004) reported that the

more assistance FCGs gave to the patient in activities of daily living, the more depressed they felt after the death. More than 40% of bereaved caregivers continued to have elevated levels of depression eight months after the death (Bonanno, Moskowitz, et al., 2005).

The following studies looked at both positive and negative aspects of caregiving and their influence on bereavement for FCGs. In a study by Koop and Strang (2003), bereaved FCGs of cancer patients reported several things about caregiving that were helpful to them in bereavement. For example, a sense of personal growth through caregiving provided a degree of comfort after the death and caregiving at the time of the death increased the sense of reality about it. Koop and Strang reported aspects of caregiving that were unhelpful, such as images of suffering that haunted the caregiver in bereavement as well as conflicts with family members that began during caregiving and increased after the death. Stajduhar (1997) suggested that social support during caregiving could be both helpful and challenging in adjustment to loss for AIDS caregivers. Support in caregiving from the caregiver's family of origin was helpful for bereavement adjustment as it facilitated a renewed sense of self and constructive personal changes. When family support was negative or lacking, cynicism, anger, and disillusionment contributed to difficulties in adjusting to bereavement (Stajduhar, 1997).

The role of positive experiences in caregiving may not always support better outcomes in bereavement. Higher levels of caregiver benefit also predicted higher levels of grief and depression in FCGs (Boerner et al., 2004). In a study of 217 bereaved FCGs, Boerner and her colleagues (2004) found that positive aspects of caregiving (benefits), such as feeling useful and appreciating life more, were related to increased grief scores and more depressive symptoms after the death. Several studies have suggested possible explanations

for this. The loss of the meaningful role of caregiver may be a further strain for bereaved FCGs and the loss of an important and positive relationship leads to more intense grief (Boerner et al., 2004; Bonanno, Moskowitz, et al., 2005; Ferrario, Cardillo, Vicario, Balzarino, & Zotti, 2004). Findings from these studies are important as they suggest that improving patient care and FCG benefit before the death may help FCGs with some aspects of their bereavement but may not necessarily reduce the distress that FCGs experience.

In summary, bereaved FCGs are affected by the stress of caregiving and of bereavement. There is a considerable and growing body of knowledge about the effects of FCGs' experiences in caregiving on their health and well-being. Current literature also provides increasing insight into the complex effects of various aspects of caregiving experiences that affect FCGs' adjustment in bereavement. Experiences of caregiving, both negative and positive, have continuing consequences for FCGs that shape their bereavement experiences and adjustment. It is crucial to understand that FCGs' needs do not end with the patient's death. It is also important for health care professionals to understand not only FCGs' experiences of caregiving but also their bereavement experiences and the helpful and challenging aspects of these experiences that can influence adjustment. Currently, there is limited knowledge about FCGs' experiences in bereavement and the effects that these experiences have on adjustment in bereavement. This area warrants further investigation to inform health care professionals in their interactions with bereaved FCGs.

Bereavement Adjustment

For this section, I reviewed studies from a number of areas related to bereavement adjustment. These included: (1) the impact of bereavement on FCGs and other bereaved persons, (2) historical influences on theory and research in bereavement, (3) current

models of bereavement coping and adjustment in relation to bereavement, and (4) variables that can influence bereavement outcomes for FCGs and other bereaved persons.

The Impact of Bereavement

The death of a close family member can be an extremely stressful life event with implications for the bereaved person's health and well-being. Grief is the usual reaction to the loss of a significant other through death and includes diverse psychological and physical manifestations (Stroebe et al., 2001). Based on existing research knowledge, Stroebe and her colleagues (2001) suggested that bereavement is a complex process which is ongoing and possibly life-long. Bereavement has well-known detriments to personal health and well-being. A recent review of the bereavement literature drew together information illustrating that bereaved people were more vulnerable to disease and were at increased risk for mortality, especially in the early months after the death (Stroebe, Schut, & Stroebe, 2007). Decreased immunological function in the first four to fourteen months of bereavement affected vulnerability to health problems (Goodkin, Baldewicz, Blaney, Asthana, Kumar, Shapshak, et al., 2001). Carter (2005) reported that bereaved FCGs had severe sleep disturbances that affected their ability to accomplish daily tasks. Bereaved individuals are known to be at increased risk for anxiety and depressive symptoms (Chochinov, Holland, & Katz, 1998). Symptoms of grief continued to be prominent in FCGs for 13 months or longer following the death (Chentsova-Dutton et al., 2002). Studies of bereaved spouses found that widows and widowers experienced increased levels of both social and emotional loneliness (Stroebe, Stroebe, Abakoumkin, & Schut, 1996; van Baarsen, 2002). The impact of bereavement affected a person's functioning across cognitive, physical, emotional, social, and spiritual domains (Cairns, Thompson, & Wainwright, 2003).

Bereavement also impacts FCGs' families and communities. In a study of 115 adult families, Kissane and McKenzie (1997) found that the loss of a family member impacted overall family coping. The family's coping had strong negative correlations to levels of depression, distress, and social adjustment for the individuals within the family (Kissane & McKenzie, 1997). The impact of bereavement on individuals and families has ramifications at the community level in terms of work and health care systems. The number of work days lost because of bereavement can put financial strain on bereaved employees and their employers (Ferrario et al., 2004). In the United States, estimates of the cost of bereavement in the workplace reached \$37.5 billion (Center for Advancement of Health, 2003). For recently bereaved people, increased use of the health care system included more physician visits and increased use of health services (Charlton, Sheahan, Smith, & Campbell, 2001; Wyatt et al., 1999). Bereaved individuals and families are, at least temporarily, unable to contribute to society in their usual way following the death of a significant person.

Historical Influences on Theory and Research

The historical influences of theory and research in grief and bereavement are reviewed to establish the roots of our current knowledge in this field. From early investigations of grief and bereavement onwards, certain topics have had significant influence and continue to arise in the discourse about bereavement. These topics include pathological grief, intervention with bereaved people, the concept of grief work, an ongoing relationship with the person who died, searching for meaning related to the loss, and approach and avoidance of expressions of grief. These topics are introduced here and discussed more fully in later sections.

Two seminal works, one by Freud (1917) and the other by Parkes and Weiss (1983), introduced these topics into the field. In *Mourning and Melancholia*, Freud (1917) suggested that, "Although mourning involves grave departures from the normal attitude to life, it never occurs to us to regard it as a pathological condition and to refer it to medical treatment. We rely on its being overcome after a certain lapse of time, and we look upon any interference with it as useless or even harmful" (p. 23). Freud presented his views that grief was worked through and that an internalized relationship with the person who died was created. Freud's theoretical observations on mourning have had a lasting impact on grief and bereavement research. Ideas about whether grief may be a pathological condition, whether intervention can be helpful or harmful, the importance of the work of grief or "grief work", and the benefit of an ongoing relationship continue to influence current conceptions of grief. The Harvard Bereavement Study (Parkes & Weiss, 1983), begun in 1965, was a longitudinal study of younger bereaved spouses over a four-year period, using both qualitative and quantitative methods. This seminal study introduced the concepts of searching for the meaning of the death and the approach and avoidance of expressions of grief.

Although Freud (1917) differentiated grief, which he did not regard as pathological, from the pathology of melancholia, later investigators described pathological forms of grief. Lindemann's (1944) detailed descriptions of grief after traumatic loss distinguished characteristics of acute grief and described delayed grief and distorted grief as morbid grief reactions. Bowlby's (1969) work on attachment and loss

and the Harvard Bereavement Study (Parkes & Weiss, 1983) also described aberrations in grief reactions. The patterns of unresolved and abnormal grief identified in these early studies have given way to the current descriptions and definitions of traumatic or complicated grief and arguments for the designation of it as a unique diagnosis (Horowitz, Seigel, Holen, & Bonanno, 1997; Prigerson et al., 1995).

It never occurred to Freud (1917) to refer grief for medical treatment and he thought that intervening with grieving would be useless or possibly harmful. By Lindemann's (1944) time, psychiatric treatment for certain mourners was well established. In the current discourse about intervention, this dichotomous view continues. On one side, individuals who are experiencing, or at risk for, complicated grief should receive psychotherapeutic intervention (Zhang et al., 2006). On the other, intervention is not deemed necessary or beneficial for those who do not have complicated grief (Neimeyer, 2000; Schut et al., 2001).

Freud's (1917) concept of "grief work" described how the bereaved person detached from the person who died and how emotional energy (libido) became available for other attachments. Parkes and Weiss' (1983) presented a similar concept, obsessional review, that described the need of many bereaved people to go over and over the circumstances of the death. Grief work and obsessional review were seen as a necessary expression of emotion and search for understanding related to the death of someone close (Bowlby, 1969). However, current thinking is that grief work is similar to rumination and frequent expression of negative emotions. These latter behaviours are not considered to be helpful and may even be harmful (Bonanno, Papa, LaLande, Zhang, & Noll, 2005; Stroebe, Boelen, van den Hout, Stroebe, Salemink, van den Bout, 2007).

Although Freud emphasized that the bereaved person detached from the person who died to free emotional energy, he also suggested that another goal of detachment was to internalize a continuing relationship with the person who died. Much discussion has ensued about whether one or the other, detachment or an ongoing relationship, is more efficacious to adjustment in bereavement (Stroebe & Schut, 2005). Recent research focuses on a more integrated view of these aspects of bereavement (Stroebe & Schut, 2005). Klass (2006) described a continuing relationship (bond) as a normal experience in bereavement that may or may not be helpful to the bereaved individual.

The work of Parkes and Weiss (1983) described the need for bereaved individuals to search for the meaning of the death and loss. This need continues to be studied as meaning-making, which includes making sense of the loss and finding benefit in the experience. Both meaning-making and benefit-finding are considered to be helpful to adjustment in bereavement (Davis, Nolan-Hoeksma, & Larson, 1998; Neimeyer, 2006). Parkes & Weiss (1983) also described the need for bereaved people to find some balance in the dilemma between expressing feelings and avoiding being seen as needy or burdensome because of emotional expression. This need for balance in bereavement continues to be relevant to the emerging recognition of competing expression and control processes in bereavement (Lindstrom, 2002; Stroebe & Schut, 1999). Current research suggests that expression and control are complex and, probably, culturally influenced aspects of grief and bereavement (Bonanno, Papa et al., 2005). As Lindstrom (2002) suggested, a balanced view is needed concerning what may be helpful and harmful for bereaved people as they struggle with the diversity and intensity of grief responses.

Current Models of Bereavement Coping and Adjustment

Lindemann (1944) first described stages of the grief process and basic tasks that the bereaved person strives to accomplish. Later, Bowlby (1969) and Parkes and Weiss (1983) described different phases and tasks for the grief process. Conceptions of phases and tasks in normal bereavement were also proposed by Kubler-Ross (1969), Rando (1984), and Worden (2003). These models have had, and continue to have, significant impact on clinical practice and society's views of grief and bereavement (Breen & O'Connor, 2007). Stage models have been mistaken for prescriptive rather than descriptive models of bereavement. These stage or task models are not currently valued in bereavement research and are considered too linear to capture the complexity of grief and bereavement. There are now non-linear models of grief and bereavement that address the complexity of these experiences and the processes involved in adjustment in bereavement.

Two such models of bereavement, that influenced my understanding of adjustment in bereavement and the framework from which this study was launched, are presented in this section. These models are the model of adaptation to bereavement (Shuchter & Zisook, 1993) and the dual process model of coping in bereavement (Stroebe & Schut, 1999). This section also includes a model of adjustment to chronic illness (Stanton, Collins, & Sworowski, 2001) that contributed to my understanding of the contexts of adjustment and to the study's initial framework.

The model of adaptation to bereavement (Shuchter & Zisook, 1993) provides a multi-dimensional model of bereavement adaptation encompassing six dimensions of grief. Within the *emotional and cognitive experiences* dimension, emotional experiences include grief reactions that are initially intense, change over time, and do not completely

go away. Cognitive experiences include recognition, appraisal, and acceptance of the changes that accompany the loss. *Coping with loss* includes both positive and negative coping strategies such as social involvement or social isolation. A *continuing relationship with the person who died* comes from the relocation of that relationship to the mental and spiritual realms. The *functioning* dimension encompasses mental and physical health, social and occupational performance, and the bereaved individual's independence. *Social and intimate relationships* include social support from family, friends, and other bereaved individuals. It also includes the development of new relationships. The dimension of *identity* comprises a bereaved individual's personal strengths and positive view of him or herself.

Strengths of Shuchter and Zisook's (1993) model of adaptation to bereavement include, for example, that there is room for considerable individual difference within the broad range of bereavement experiences described by the dimensions. Also, an individual may demonstrate varying levels of adaptation across the different dimensions. However, the adaptation to bereavement model lacks any suggestion of a process to explain how adaptation or adjustment may occur.

The dual process model of coping in bereavement (Stroebe & Schut, 1999) suggests such processes. This is a model of coping that describes specific stressors of bereavement, cognitive strategies, and a process of oscillation. Bereavement stressors fall into two distinct categories. Loss-oriented stressors are the loss experience itself, emotional reactions to the loss, and the grief work undertaken by the bereaved individual. Restoration-oriented stressors are secondary stressors such as change that accompanies the loss, reorganization of the individual's life, and the emotions related to these. The

cognitive strategies described in the dual process model of coping in bereavement are denial, confrontation, and avoidance. Coping in bereavement takes place in the context of everyday life and denial allows a bereaved individual to take time away from stressors and coping. Stroebe and Schut described a dynamic process of oscillation that permits stressors to be coped with concurrently. This regulatory mechanism is an alternation between confrontation and avoidance of loss-oriented and restoration-oriented coping. Stroebe and Schut suggested that the oscillation process is necessary for optimal adjustment.

The dual process model of coping in bereavement (Stroebe & Schut, 1999) is a useful explanatory model of the process by which bereaved individuals are able to cope with both the demands of grief and the changes that accompany loss. However, it does not address the influence of context, that is the personal, social, situational (e.g., caregiving, death), and environmental (e.g., community, culture) aspects of individual circumstances, on the bereavement experiences of bereaved individuals.

The model of adjustment to chronic illness (Stanton et al., 2001) presented here is an example of a model of adjustment processes. The model of adjustment to chronic illness was useful to the study's initial framework as bereavement also has chronic elements and health consequences. The model of adjustment to chronic illness is founded on contextual stressors, cognitive appraisals, and coping processes. Contextual stressors are not limited to a specific stressor (chronic illness) but are seen as interconnected elements of personal, situational, and interpersonal and environmental contexts. Overall adjustment is a summation of levels of adjustment in psychological, social, and health dimensions. The model of adjustment to chronic illness has similarities to the

bereavement models presented. Like the adaptation to bereavement model, the model of adjustment to chronic illness includes the potential of differing levels of adjustment over different dimensions. Like the dual process model of coping in bereavement, the model of adjustment to chronic illness includes coping processes related to particular situational stressors (bereavement, illness). The relevant strength of the adjustment to chronic illness model is that it includes elements of context beyond the situational. The bereavement literature suggests that contextual factors, such as age, gender, caregiving, circumstances of the death, and culture, impact bereavement experiences and outcomes (Cherlin, Barry, Prigerson, Schluman-Green, Johnson-Hurzeler, Kasl, & Bradley, 2007; Ferrario et al., 2004; Klass, 2006; Stroebe, Stroebe, & Schut, 2001).

Each of the three models presented above contributes to an understanding of the complex processes of adjustment in bereavement. Shuchter and Zisook's (1993) model of adaptation to bereavement acknowledged the variation of experiences and adaptation within and between individuals. Stroebe and Schut's (1999) dual process model presented dynamic processes of coping in bereavement that influence adjustment. The model of adjustment to chronic illness (Stanton et al., 2001) provided understanding of the context and its elements within which adjustment occurs. Together these models accommodate much of the shared human aspects of bereavement experiences and of the unique aspects of individual experience.

Influences on Bereavement Outcomes

In this section, knowledge is presented relating to variables that can influence bereavement outcomes. These variables may point to indicators of what may be helpful and may be challenging to FCGs in adjusting to their loss. This review of the literature found few

studies of FCGs in palliative care that directly addressed what occurs during bereavement that was helpful and challenging. Findings from these and more general studies of bereaved individuals indicate that certain variables occurring in bereavement can influence adjustment. The focus in this section is on variables or influences that may be amenable to change or control, either by bereaved individuals themselves or with assistance from a health care professional. For the purposes of organization, examples from the literature regarding these variables that influence adjustment in bereavement are presented within social, cognitive, emotional, physical, and spiritual domains of human functioning (Cairns et al., 2003).

Within the *social* domain, investigations have focussed on several aspects of social support in bereavement, such as increase and decrease in social support following a death, loneliness, family support, and support from other bereaved people. The general health benefits of social support are well-established (Wills & Fegan, 2001). However, the effects of social support in bereavement are not so clearly beneficial, possibly due to the complex nature of providing support to a bereaved person (Lehman, Ellard, & Wortman, 1986). In a qualitative study of spouses and parents who had experienced a sudden, unexpected loss (motor vehicle crash), Lehman and his colleagues (1986) asked respondents to indicate helpful and unhelpful social support efforts. They found that the same person (often a family member or close friend) was the source of both helpful and unhelpful social support efforts. Examples of helpful social support behaviours included contact with similar others, opportunities to vent feelings, and expressions of concern. The authors suggested that family and friends avoid encouraging early recovery or giving advice as these were the most commonly reported unhelpful social support behaviours.

Several studies investigating increases and decreases in social support following the death of a family member demonstrated the effects of these changes on adjustment in bereavement. In a study of 93 middle-aged widows, low levels of social support were identified as a risk factor for negative emotional reactions and low mental health scores (Ungar & Florian, 2004). In this study, the widows distinguished between relationships with family, which grew stronger after the death, and relationships with friends that sometimes weakened and disappeared. In contrast to the above, Chentsova-Dutton and Zisook (2005) found that widows and widowers in the San Diego Widowhood study reported improved relationships with both family and friends and increased support throughout the first year of bereavement. These conflicting findings demonstrate that changes in social support following a death occur in somewhat unpredictable ways. However, increases in social support from family seemed to predict better bereavement outcomes (Chentsova-Dutton & Zisook, 2005) and decreases in social support were linked to poorer adjustment to bereavement (Ungar & Florian, 2004).

Social support has also been studied in relation to aspects of loneliness experienced in bereavement. Social and emotional loneliness are common experiences among widows and widowers (Stroebe et al., 1996; van Baarsen, 2002). Social loneliness is a lack of perceived social support and integration; emotional loneliness is a sense of lacking reliable attachments to others. In a longitudinal study of 101 older widows and widowers, van Baarsen (2002) found that both social and emotional loneliness increased after the death and that emotional loneliness persisted for longer than two and a half years. Van Baarsen (2002) also found that increased support from the social network after a partner's death had a mitigating effect on emotional loneliness. However, this increase in social support following the death did not

alter levels of emotional loneliness until one and a half years after the death. In contrast to this finding, in a study of 60 widows and widowers under retirement age, Stroebe and her colleagues (Stroebe et al., 1996) found that social support from family and friends helped with social loneliness but did not significantly reduce emotional loneliness for bereaved spouses even at 2 years after the loss.

Family support is a particularly important aspect of social support for FCGs in palliative care, both before and after the death of the ill family member (Bernard & Guarnaccia, 2003; Kissane & McKenzie 1997; Stajduhar, 1997). Much of grief and adjustment in bereavement occurs within the context of the bereaved family. Stajduhar (1997) suggested that the quality of social support from other family members during caregiving had an impact on adjustment in bereavement for family caregivers of AIDS patients. Kissane and McKenzie (1997) suggested that family response to bereavement was influenced by, and in turn had an influence on, the responses of the individuals within the family. They found that the family was the primary source of social support for grief and bereavement and that family coping was an important indicator of the social support available to its members. Further, the bereaved spouse's perception of overall family coping in bereavement was consistently correlated to bereavement outcome measures, such as intensity of grief, psychological distress, and social adjustment. Kissane & McKenzie (1997) suggested that this finding demonstrated that when family coping was seen as poor, outcomes were poor, and when family coping was seen as adaptive, outcomes were good. It may also indicate that bereaved spouses were able to assess their families' functioning accurately.

Connection with other bereaved persons may be beneficial in adjusting to loss (Lehman et al., 1986). Bereaved FCGs of “elderly relatives” (p. 299) preferred emotional support from others with similar experiences of caregiving and bereavement over support from those with only caregiving experience or no similar experiences (Suitor & Pillemer, 2000). Widows and widowers in the San Diego Widowhood Study sought out connections with other widowed people through bereavement support groups (Chentsova-Dutton & Zisook, 2005).

Various aspects within the *cognitive* domain such as self-efficacy, positive states of mind, rumination, and cognitive interpretations have been investigated relating to their influences on bereavement outcomes. Bereavement coping self-efficacy (BCSE), an aspect of personal cognition concerning beliefs about one’s own capabilities to cope in bereavement, was investigated by Benight, Flores, and Tashiro (2001). In a study with 101 cancer widows, they found that widows with higher BCSE scores reported better psychological and spiritual well-being. They suggested that BCSE may be amenable to change through direct mastery experiences, i.e., success in coping, and through the modelling of effective coping by other widows (Benight, Flores, & Tashiro (2001). For caregiving partners of men with AIDS, positive states of mind, such as productivity and focussed attention, were significant indicators of positive recovery from depressive mood in bereavement (Moskowitz, Folkman, & Acree, 2003). Rumination may be an unhelpful behaviour for bereaved individuals. Bonanno, Papa, and their colleagues (2005) found that rumination predicted long-term distress and poorer perceived health populations of bereaved parents and spouses. This cross-cultural comparative study found that higher levels of rumination predicted poorer bereavement outcomes for both bereaved American

spouses and parents and for parents and spouses from the People's Republic of China (Bonanno, Papa, et al., 2005). In a study of 234 participants who lost a first degree relative (partner, parent, child, or sibling), Boelen and his colleagues (2003) looked at the role of negative interpretations of grief reactions on levels of grief-related distress. They found that if bereaved individuals have negative interpretations of their grief reactions, they are likely to experience distress and discomfort. If these reactions are interpreted as normal parts of recovery, then distress is less likely to occur. Also, study results suggested that negative interpretations of grief reactions and grief-related distress influenced the frequency with which bereaved individuals used avoidance strategies that hindered adjustment in bereavement. This study is particularly interesting as it may point to intervention strategies that normalize grief in order to prevent elevated levels of distress.

Within the *emotional* domain, balancing approach and avoidance of grief may be important for adjustment in bereavement (Lindstrom, 2002; Stroebe & Schut, 1999). Lindstrom (2002) suggested that grief work, a focus on expressing grief and working through the emotional impact of the loss, as originally suggested by Freud (1917), may or may not be helpful depending on the intensity of focus given to it. In the study mentioned earlier concerning rumination, Bonanno, Papa, and colleagues (2005) also found that grief work increased distress, while grief avoidance (avoiding thinking, talking, or expressing feelings about the loss) predicted poorer perceived health. Lindstrom (2002) and Stroebe and Schut (1999) have suggested that a balance between reacting and responding to the loss and avoiding grief when it becomes too burdensome may be most helpful. The presence of positive emotions, such as humour and love, in conjunction with the negative emotions of

grief, such as sadness and longing, were found to have a beneficial influence on outcomes for recently bereaved older widows (Ong, Bergeman, & Bisconti, 2004). In a daily diary study with 34 widows, Ong and his colleagues (2004) found that, while all of the widows experienced similar levels of negative emotion, those who also reported more positive emotions experienced lower levels of stress and depression.

In regard to the *physical* domain, it is well-known that health may be affected in bereavement (Zapart et al., 2007; Kissane et al., 1994). Although increased use of the health care system is reported (Charlton et al., 2001; Wyatt et al., 1999), there is little information about the health behaviours of bereaved individuals, that is, what individuals do to maintain or improve their health and physical well-being. Chentsova-Dutton and Zisook (2005) reported that, for the widows and widowers in the San Diego Widowhood Study, maintaining daily routines and self-care practices were beneficial. There is some indication that leisure activities, which may be considered a form of self-care, enhanced life satisfaction for middle-aged widows (Ungar & Florian, 2004). Studies of health behaviours in bereavement are limited and knowledge is needed about what is challenging and what is helpful to FCGs in terms of their own health.

In the *spiritual* domain, the issues of meaning-making and an ongoing relationship with the person who died are current issues in the bereavement literature. In a study of bereaved FCGs of hospice patients, Davis, Nolen-Hoeksema, & Larson (1998) found that two distinct aspects of meaning-making, that is, making sense of the loss and finding benefit in a challenging situation such as the death of a significant person, influenced adjustment in bereavement. Making sense of the loss was associated with lower levels of distress in the first year after the death while finding benefit was associated with decreasing distress over

time beyond the first year (Davis et al., 1998). Maintaining an ongoing relationship with the person who died may provide solace for some bereaved spouses depending on cultural and personal characteristics and the length of time since the loss (Chentsova-Dutton & Zisook, 2005). An ongoing relationship has also been called “continuing bonds”, a term introduced by Klass and his colleagues in 1996 (Klass, 2006). In a summary article in a special issue of *Death Studies* (2006, issue #30), Klass cautioned that although there was evidence to suggest positive interaction between continuing bonds and adjustment in bereavement, there was also evidence to suggest the converse. Rather than any causal relationship, Klass (2006) proposed the need for models of a complex interaction between continuing bonds and adjustment.

In each of the domains above, there are studies of variables that are associated with adjustment in bereavement. However, few of these studies focussed on FCGs in palliative care and their bereavement experiences. Knowledge is needed about what is challenging and what is helpful to FCGs in terms of their adjustment to the loss of a significant person. Such knowledge could guide health care professionals in their interactions with bereaved FCGs.

Bereavement Care

In considering the bereavement care needs of FCGs with uncomplicated grief, it is useful to understand the prevalence of uncomplicated grief in a bereaved population. Kristjanson and colleagues (2005) found that the majority (93%) of bereaved FCGs in hospice palliative care fell into categories of low risk and moderate risk for difficulty in bereavement (Kristjanson, Cousins, Smith, & Lewin, 2005). The individuals in both of these categories were considered to have uncomplicated grief and to require less intensive bereavement care than those individuals with complicated grief. Prigerson and her colleagues (1995) found that 80% of the bereaved population in their study had uncomplicated grief and

20% of the population had complicated grief (Prigerson, Frank, Kasl, Reynolds, Anderson, Zubenko, et al., 1995). In these studies, the researchers found that a minority of FCGs (7 – 20%) had complicated grief (Kristjanson et al., 2005; Prigerson et al., 1995). Although uncomplicated grief is not as intense and intrusive as complicated grief, uncomplicated grief can include many challenging responses and adaptive difficulties (Chentsova-Dutton & Zisook, 2005; Stroebe et al., 2001).

Many bereaved FCGs (30% - 50%) request assistance and support from health care professionals (Brazil, Bedard, & Willison, 2003; Wyatt et al., 1999). As the majority of bereaved individuals have uncomplicated grief, most of these FCGs will have uncomplicated grief also. When FCGs with uncomplicated grief approach the health care system for assistance with their grief and adjustment in bereavement, health care professionals need to respond in a helpful, not harmful, way. However, the literature remains unclear about what kinds of bereavement care are beneficial to bereaved individuals with uncomplicated grief. In a review of risk assessment for complicated grief, Walsh-Burke (2000) suggested that bereaved individuals would present a spectrum of levels of risk and, therefore, an associated spectrum of bereavement care needs. Further, bereaved individuals with low and moderate levels of risk (uncomplicated grief) would have a variety of bereavement care needs and these needs would be quite different from the needs of those with high risk for complicated grief (Walsh-Burke, 2000). Bereaved individuals with complicated grief are known to benefit from psychotherapeutic bereavement care such as individual psychotherapy, group therapy, or psychiatric care (Schut et al., 2001). For bereaved individuals with uncomplicated grief, there is little knowledge about the challenges they face and about what kinds of bereavement care may be beneficial.

A current discourse about bereavement care is pertinent to the study of what may be helpful or challenging for bereaved FCGs. Freud's suggestion that interventions for bereaved individuals may be "useless or even harmful" (Freud, 1914, p. 23) is echoed in current discourse about who should receive bereavement care and what that care should be. An often-quoted contention in this present discourse is that intervention for people with uncomplicated grief is not helpful and, possibly, may be detrimental (Neimeyer, 2000). Several articles concerning bereavement interventions (Forte, Hill, Pazder, & Feudtner, 2004; Neimeyer, 2000; & Schut et al., 2001) are useful to understanding this discourse.

First, a meta-analysis of the effectiveness of bereavement intervention was reported by Neimeyer (2000) from an unpublished dissertation by Fortner, completed in 1999. According to Neimeyer (2000), Fortner found a significant positive effect size ($d = 1.3$) for intervention and that individuals with complicated grief benefited from therapeutic interventions. Reportedly, Fortner also found that intervention for people with *uncomplicated* grief was detrimental to their well-being. He found that approximately one third of participants, most of them with uncomplicated grief, experienced treatment-induced deterioration - being worse off than if they had been assigned to the control condition. This is a serious assertion that requires careful attention and there is some controversy about it discussed later.

Second, a narrative review and critical assessment by Schut and his colleagues (2001) looked at 30 bereavement intervention studies. These included: a) 16 studies of primary preventive interventions, open to all bereaved people, such as mutual help, educational, and socialization groups; b) 7 studies of preventive interventions for high-risk groups, such as individual counselling and hospice bereavement support; and c) 7 studies of interventions

aimed at the treatment of complicated grief, such as systematic desensitization and dynamic therapy. The studies covered a range of losses involving bereaved adults and bereaved children. Schut and his colleagues cautiously concluded that the more complicated the grief process, the better the chances of intervention leading to positive results. They also suggested that caution be used in outreach preventive intervention programs that include all bereaved people because studies using outreach recruitment methods were less effective in reducing grief-related symptoms than studies recruiting people who asked for help. Schut and colleagues (2001) concluded that intervention with bereaved individuals with complicated grief showed modest and lasting results, while no clear results could be claimed for those with uncomplicated grief. However, it may be important to note that along with participants' increasing levels of bereavement risk/complication, studies had increasing levels of design adequacy (for example, pre- and post-test design, randomization, and control groups) and intervention sophistication. There would also have been greater room for measurable improvement within individuals with more complicated grief and measurement tools would more easily detect changes.

Third, in another review of bereavement intervention, Forte and her colleagues (Forte, Hill, Pazder, & Feudtner, 2004) provided further evidence of the problems among intervention studies. They conducted a systematic review of 74 studies of interventions to reduce bereavement-related symptoms and concluded that, based on the available evidence, no recommendations could be made regarding interventions with bereaved individuals (Forte et al., 2004). This conclusion was based on excessive between-study variation, theoretical heterogeneity, and the lack of replication studies. Within studies, the authors found common, recurring methodological flaws in study design and widespread inadequate reporting of

intervention procedures. The authors specifically stated that substantial variation of outcomes and measures among studies precluded use of any generic effect-size measures.

The report by Neimeyer (2000) and review by Schut et al. (2001) have been cited as the basis for cautions that intervening with bereaved individuals with uncomplicated grief is unproductive and unnecessary (Department of Human Services, 2004; Center for the Advancement of Health, 2003). It has been suggested that health care professionals should focus their attention on individuals with complicated grief and leave individuals with uncomplicated grief to manage with their natural supports (Aranda & Milne, 2000; Center for the Advancement of Health, 2003). The empirical foundation for such cautions needs to be considered very carefully. The findings of treatment-induced detriment to bereaved individuals with uncomplicated grief reported by Neimeyer (2000) have been cited in subsequent articles and in the popular media (Larson & Hoyt, 2007). However, the empirical evidence of Fortner's meta-analysis has never been published and the methods, statistical analysis, and findings have not been peer-reviewed. Although the meta-analysis included 23 bereavement intervention studies involving both children and adults, across all types of loss and a range of interventions, no further details of the studies are given by Neimeyer (2000). Schut and his colleagues (2001) were guarded in the conclusions they drew from their findings. They pointed out that their conclusions were not definitively substantiated by the empirical studies as there were serious methodological flaws in many studies, inconsistent results, and gender differences that affected results. Forte et al. (2004) found that few reliable conclusions are available to guide health care professionals in providing bereavement care.

Recently, Larson and Hoyt (2007) published a review of the evidence for the contention that intervention was detrimental to a substantial portion of the bereaved

population, called the treatment-induced deterioration effects (TIDE). They critiqued Fortner's dissertation (1999), as the original source of the TIDE contention. They suggested that the statistical measure used by Fortner was flawed and, therefore, so were the findings of detriment to bereaved individuals through bereavement interventions. Larson and Hoyt (2007) also suggested that, following Niemeyer's (2000) report, the TIDE findings were widely accepted as valid and reliable without sufficient scientific scrutiny. They were critical of the frequent citation in the bereavement literature of the TIDE finding from a meta-analysis that had never been peer-reviewed or published. The spread of the TIDE finding into the general media led Larson and Hoyt (2007) to express deep concern that negative impressions of bereavement care interventions might discourage distressed bereaved individuals from seeking help.

Assumptions about individuals with uncomplicated grief have been made based on insufficiently rigorous evidence. These assumptions are that 1) bereaved individuals with uncomplicated grief do not need help and 2) providing help to them can be harmful. Such assumptions may affect quality bereavement care as there are implications that follow from them. The implications for policy and planning, as already evidenced by Aranda and Milne (2000) and the Department of Human Services (2004), are that bereavement care for individuals with uncomplicated grief is discouraged as unnecessary and possibly harmful and that funding for programs for this group may not be available. The implications for research are that researchers may be deterred from studying bereaved individuals with uncomplicated grief and, consequently, there may be a lack of evidence-based knowledge available to assist health care professionals. The implications for clinical practice are that appropriate care for individuals with uncomplicated grief may be compromised. If health care professionals lack

knowledge and guidance in providing bereavement care to this group, appropriate care may not be forthcoming for bereaved FCGs in palliative care who request help.

In summary, there is limited research into the bereavement experiences of FCGs in hospice palliative care. Research focussed on the needs of bereaved individuals who have uncomplicated grief, including FCGs, is needed to provide foundational information regarding what promotes adjustment to the loss of a significant other for this group. Currently, neither the bereavement care needs of those with uncomplicated grief, nor the needs of FCGs in hospice palliative care, have been articulated clearly in the literature. Little is known about the factors that are helpful and that are challenging in FCGs' adjustment to the loss of the person for whom they were caring. Foundational knowledge and understanding of influences on adjustment in bereavement are needed to guide health care professionals in their responses to FCGs and to inform bereavement care policies.

CHAPTER 3

Methods

The purpose of this study was to gain insight into the bereavement experiences of FCGs with uncomplicated grief in palliative care. Research has the potential to provide knowledge that can assist health care professionals in providing appropriate bereavement care. This study builds on existing knowledge of aspects of bereavement in order to provide a more complete description of the experiences of bereaved FCGs with uncomplicated grief. As bereavement adjustment in FCGs with uncomplicated grief has received limited attention, a qualitative research approach was used for this study.

Research Design

Interpretive description methodology (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997) was used to address the research question and objectives. This methodology was particularly suited to my research question as it recognizes that health and illness experiences, such as bereavement, are “complex interactions between psychosocial and biological phenomena” (Thorne et al., 1997, p. 172). Interpretive description involves knowing individual cases thoroughly and abstracting common themes and meanings from these cases. Knowledge of common patterns of experience informs the principles that guide response to individual cases in the practice context. In keeping with interpretive description, this investigation was located within a framework of existing knowledge from both the literature review and personal clinical knowledge. This framework provided a “foundational forestructure” (Thorne et al., 1997, p. 173) or an orientation point that informed design decisions and early data analysis. It is expected that the framework will be challenged during the analysis process (Thorne et al., 1997). Using an interpretive descriptive approach, I

investigated the experiences of individual FCGs with uncomplicated grief, as they adjusted to the loss of the person for whom they were caring, looking for the commonalities in what was helpful and challenging in order to increase understanding of adjustment in bereavement for this group. As I am a novice researcher, all work was undertaken with the direction and support of my supervisory committee.

Participants

Bereaved FCGs participated in either individual interviews (primary sample) or a focus group (secondary sample). I will report on the primary sample first and then report on the secondary sample.

Primary Sample

Participant recruitment.

In the primary sample, there were 11 participants in individual interviews. Potential participants were identified by Victoria Hospice Society (VHS) counsellors, a nurse employed by both VHS and Vancouver Island Health Authority, and a nurse research coordinator with another FCG study who knew about my study. To assist them in judging complicated grief as an exclusion criteria for participants, I reviewed the criteria offered by Prigerson & Jacobs (2001) with the counsellors, nurses, and research co-ordinator and gave a written copy to them (Appendix A). Letters of invitation (Appendix B) that provided detailed information about the study were sent by the referring health care professional to potential participants who fit the study criteria. The letter asked them to call me directly or to let the referring person know of their interest and to give permission for me to call them. This latter option allowed people to verify the origins of the invitation and to feel more confident in considering participation.

The sampling strategy appropriate for this interpretive description study was purposive sampling (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). For the purpose of garnering a range of experiences, I sought variation within the sample in terms of participants' bereavement experiences, including positive and negative experiences. I also looked for variation in the age and gender of participants, their relationship to the person cared for, the length of time since the death, involvement or no involvement with a hospice palliative care program, and use of formal and informal supports. Initial contact with participants was a telephone call during which I screened for eligibility and appropriateness, choosing participants who could inform the study. Interviews were arranged with participants whom I considered to be articulate, thoughtful, and able to relate their personal bereavement experiences. Initially those whose experiences are typical were sought, but as the study progressed participants with particular kinds of experiences and those with atypical experiences were sought (Morse, 1991). For example, in an initial phone conversation, one woman reported a lack of grief responses in bereavement and I anticipated that her experiences would be atypical. Also, three siblings were included for their potential contributions to understanding family experiences in bereavement.

Inclusion/exclusion criteria.

The participants for this study's primary sample were bereaved FCGs (a) who cared for a terminally-ill adult at home, (b) whose care recipient died between one and four years ago, (c) who were deemed by the referring professional to be experiencing uncomplicated grief, (d) were at least 19 years of age, (e) spoke English, and (f) resided in the VIHA South Island area. To establish eligibility, the definition of FCG used was from the CIHR-funded

New Emerging Team (NET) on Family Caregiving in Palliative and End-of-Life Care (Appendix A). The period of bereavement was chosen as one to four years post death as I believe it allowed participants to speak more comfortably about their experiences for two reasons. First, distress and depression are common in the first year following the death of a significant person (Bonanno, Moskowitz, et al., 2005; Chentsova-Dutton & Zisook, 2005). Greater emotional stability is likely as time since the death increases (Chentsova-Dutton et al., 2002, Worden, 2003). Second, my clinical experience suggests that a timeframe of over one year allows greater opportunities for adjustment to loss and reflection on personal progress.

Potential participants were excluded if the patient had a primary diagnosis of dementia or Alzheimer disease as there are some indications that FCGs of hospice palliative care patients may have different experiences in bereavement than caregivers of dementia and Alzheimer patients (Schulz et al, 1997). One potential participant was excluded from the study as the time since the death was only five months. In discussion with this bereaved FCG, she expressed that she still felt quite emotionally vulnerable and was relieved to forego participation.

Description of participants.

Following the guidelines for core demographics of the CIHR-funded NET on Family Caregiving in Palliative and End-of-Life Care, pertinent demographic information, such as age, gender, length of caregiving, relationship to the person who died, date and place of death, and so on, was collected (Appendix C). Information about the participants' health was collected using four questions adapted, with the assistance of my co-supervisor, Dr. Holly

Tuokko, from the SF-36 (found in McDowell & Newell, 1996). These questions were added to the Demographic Variables Form (Appendix C).

Throughout the study, I sought participants who represented a range of personal characteristics, caregiving situations, and bereavement experiences (Table 1). The sample consisted of three men and eight women who ranged in age from 23 to 86 years old. The employment status of the participants was 5 retired, 3 employed full or part time, 2 self-employed, and 1 not employed. As FCGs, the participants included 5 spouses (2 wives, 2 husbands, 1 same-sex partner), 5 daughters, and 1 sister. The length of time that FCGs were providing care ranged from 3 months to 2 years. The FCGs cared for 9 care recipients ranging in age from 51 to 102 years old. Six care situations involved hospice palliative care services and 3 did not. Time since the death ranged from 18 months to four years. Five of the FCGs had other significant losses (deaths) within 2 years of the death of the cared-for person in this study.

Secondary Sample

In order to clarify my understanding of FCGs' experiences expressed in the individual interviews, and to check the credibility and comparability of themes and conceptualizations, the preliminary findings were presented to a focus group of other bereaved FCGs. Initially, a VHS counsellor asked me to present my research and preliminary findings to a bereavement support group that she facilitated. In discussion with the counsellor, the idea of getting feedback from the group members arose and doing so through a focus group was proposed. Ethics approval was sought and granted by the Joint University of Victoria/Vancouver Island Health Authority Human Research Ethics Board.

Table 1: Demographic Information for Family Caregivers and Persons who Died

FCG Intake	Age	Sex	Time since Death	Relation to Person who Died	Months Care-giving	Diagnosis	Place of Death
11 participants	23 – 76 years	Female: 8 Male: 3	15 – 48 months	Daughter: 5 Sibling: 1 Spouse: 5	2 – 24 months	Cancer Bladder: 1 Brain: 2 Breast: 1 Lung: 2 Pancreas: 1 COPD: 1 Heart Failure: 1 Pulmonary Fibrosis: 1	Care Facility: 1 Home: 4 Hospital: 1 Hospice: 3

Group members received a letter of invitation (Appendix B) in an email from the facilitator. Letters of invitation provided detailed information about the study and asked if they would consider participating in a focus group. It explained that I would present my study findings and ask for their thoughts and feedback. Group members were to call me directly or to call the facilitator and ask her about me and my research study or to come to the next Widow's bereavement group and discuss it before the focus group begins. The facilitator offered, in her email and at the beginning of the group, to meet separately with any group member(s) who did not want to be part of the focus group. In fact, one bereavement group member chose to leave the group prior to the focus group beginning.

The total number of participants in the focus group was eight, including 6 widows, 1 facilitator, and 1 volunteer who was also a widow. I have counted the facilitator and volunteer as they contributed to the feedback. All of the participants were women. The age

range of the group was mid-40 to mid-60. The time since death for the widowed group members was from 6 months to 19 months.

Data Collection Procedure

Consistent with interpretive description methods, in-depth formal interviews were the primary data collection strategy. Qualitative research interviews allow the participant to talk freely about relevant experiences while the interviewer maintains the balance between knowledge seeking and authentic human interactions (Kvale, 1990). In early interviews, I was interested in wide-ranging accounts of what helped bereaved FCGs to adjust to their loss. Open-ended questions and prompts were used to elicit bereaved FCGs' perspectives. Interviews began with an invitation such as, "Tell me about your experiences since (person's name) died." Subsequent questions in the interview guide (Appendix D) explored specifics of the participants' bereavement and the kinds of things that had been helpful or challenging in the participant's adjustment. Other questions included: "Were there people who were helpful to you?" "Were there things you did for yourself that helped you?" "Can you give me an example?" Later, the interview guide was altered and conversations included more focus on early conceptualizations from preliminary analysis.

I conducted each interview. Ten of the 11 individual interviews took place in the participants' homes, with the exception of one participant who preferred to come to the university. An office at the Centre on Aging was used for this interview. Interviews were approximately 60 to 90 minutes in length. The interviews were transcribed by an experienced research transcriptionist. I carefully reviewed and corrected each transcript while listening to the audio recording of the interview.

Data Analysis

In keeping with the qualitative research tradition generally, and interpretive description specifically (Thorne et al., 1997), data from this study were analyzed using inductive analysis. This is a process in which the researcher identifies commonalities or patterns by inference from the specific instances evident in the data (Morse & Field, 1995). The aim of interpretive descriptive analysis is to create a new understanding that is accessible to clinicians and adds to their knowledge (Thorne et al., 2004). The purpose of analysis is “moving beyond the theoretical framework from which the investigation was launched” (p. 9), so that analysis moves toward new and meaningful interpretations of the phenomena under investigation. The theoretical understanding gained from review of the literature, along with my research question and the interview guide (Appendix D), provided a framework for beginning analysis. In analyzing the data, caution was taken to avoid retaining this framework or bringing premature closure in analysis, both of which limit conceptualizations (Thorne et al., 1997; 2004).

The recommended analytic techniques for interpretive description include concurrent data collection and analysis, constant comparative analysis, and iterative analysis (Thorne et al., 2004). Periods of immersion in the field alternate with periods of immersion in the data (Thorne et al., 1997). *Concurrent data collection and analysis* was organized in the following way. Initially, I alternated conducting two or three interviews and familiarizing myself with these interviews by reviewing and rereading them. Initial sampling and analysis informed further sampling as I began to identify commonalities and topics to be discussed. Participants with different experiences were sought and interview questions were refined for later interviews. Approximately half of the interviews were conducted and analyzed in these

small clusters. Then, later interviews were conducted, reviewed, and analyzed one at a time for the purposes of checking and challenging conceptualizations. *Constant comparative analysis* compares and contrasts all data to all other data to facilitate understanding the relationships between and among the pieces (Thorne, 2000). Each interview transcript was reviewed and reread in detail to become familiar with the essential features of the individual stories and to get thorough immersion in the data set as a whole. Thus, prior to coding, I was able to identify patterns of experience that informed coding. As I coded the data, I identified themes and noted similarities and differences across participants. I sought to understand the range of variations in the data and to test possible explanations for fit against the data. *Iterative analysis*, that is, moving in and out of the detail of the data so that the larger context of the interviews and of the experiences of the participants remains central to the analytic process, is suggested by Thorne et al. (2004). As I theorized and interpreted meaning from the data, I returned again and again to the data to test conceptualizations both within and across participants. I questioned conceptualizations and abstractions to develop the best and simplest explanation for the data. As analysis proceeded, initial themes and linkages were refined and interpretations reconceptualised. The coding, conceptualizations, and abstractions were checked and validated by members of my supervisory committee.

Data from the focus group were transcribed, coded, and compared to data from the individual interviews and the preliminary findings.

Rigor

Strategies for ensuring the rigor and trustworthiness that are appropriate for qualitative research using interpretive description were used in this study. Trustworthiness, according to Lincoln and Guba (1985), includes four aspects relevant to qualitative research;

truth value or credibility, applicability, consistency, and neutrality. These aspects are discussed in this section and how they were applied to this study.

Truth value or credibility comes from the richness of the data arising from thorough investigation of the phenomena and from the clarity of reporting the perspectives of the participants (Morse and Field, 1995). I believe that I was able to elicit and encourage bereaved FCGs' stories in deep and detailed ways that enhanced the thoroughness and richness of my data. Credibility, whether conceptualizations are representative of shared realities, is checked through bringing conceptualizations to individual participants for critical consideration (Thorne et al., 1997). Morse and Field (1995) suggest that it is important to bring the entire model to participants and ask for their responses. The complete preliminary findings from this study were presented to a focus group of widows who were asked for both positive and critical feedback. Care was taken to encourage focus group members that critical feedback would be very helpful. In fact, their critical feedback assisted with reconceptualisation and presentation of the findings within the holistic context of the data.

Applicability, that is, whether findings apply to other contexts or with other groups, may be limited by the small sample size (Morse & Field, 1995). However, I strove for rich, thick description of the bereaved FCGs' experiences to further the applicability of my research (Creswell, 1998). I came to know the individual cases thoroughly and, thus, was able to identify similar experiences and patterns of behaviours across cases. The focus group members said that the findings reflected much of their experiences also.

Consistency relates to the idea that findings would be the same if the inquiry was replicated with the same or similar participants. In qualitative research, however, the emphasis is not so much on replication as on variations in the experiences of interest and the

uniqueness of individual experience (Morse and Field, 1995). Creswell (1998) quotes a metaphor from Richardson (1994) that captures consistency in qualitative research. The central image of the metaphor is the crystal, which is symmetrical and multidimensional, but grows, changes, reflects externalities, and refracts internally. The researcher's approach or "angle of repose" will shape what facets he or she sees within the complex structure of a phenomenon. Consistency in this study is supported by consistency in the interview technique, the accuracy of transcription, and my thorough immersion in the data. These aspects of consistency helped to ensure that findings were grounded in and supported by the data.

Neutrality is supported by freedom from bias in the research procedures and results (Morse & Field, 1995). Methodological coherence in the research procedures was addressed through careful consideration, with my supervisory committee, of each step in the design, sampling, and analysis guided by the requirements of interpretive description (Thorne et al., 1997; 2004). Reflexivity has a number of roles in research that enhance rigor. The researcher strives to be aware of his or her own biases, beliefs, and assumptions. The researcher considers his or her impact on the study through decisions made, questions asked, and relating to the study's participants. Another role of reflexivity is for the researcher to acknowledge the ways in which the experiences of doing the research affect the researcher (Dowling, 2006; Kingdon, 2005).

Reflexivity and reflective practices document and guide the processes of interpreting data and assist in protecting against researcher bias skewing the data (Thorne et al., 1997). In analyzing the data, I was aware of how my pre-existing knowledge of bereaved FCGs might influence my thinking. In order to keep true to the data, I checked

my conceptualizations by returning to and comparing the data at every stage of analysis. In my research journal, I recorded my process of interpreting data, logged discussions with my supervisory committee, and synchronized these recordings with the data (Morse & Field, 1995), in order to document the analytic directions taken (Thorne et al., 1997).

In terms of researcher bias, I came to this study with beliefs and assumptions based on the literature and on my own clinical knowledge. These beliefs and assumptions included: (1) bereaved FCGs with uncomplicated grief may need and benefit from intervention, (2) this intervention will be different than the interventions that are helpful to bereaved people with complicated grief, and (3) hospice and palliative care programs currently provide interventions for bereaved FCGs with uncomplicated grief. I recognized that these assumptions could influence how I conducted interviews, interpreted data, and conceptualized findings. I kept journal entries to articulate how my assumptions and beliefs, or my biases, arose in the process of data collection and analysis.

Other reflective practices included conversations with other student and academic researchers and discussions with my committee members. I relied on my committee members to ask challenging and thought-provoking questions. In interviews, I consciously set aside my familiar counsellor role, that is to assess grief process, to identify problems, and to create a plan. This allowed me to be grounded in my researcher role and helped me to be aware of my language, to focus on the questions and topics of interest, and to encourage clarification from participants. Also, I sought participants who challenged my beliefs and assumptions. For example, one participant, whose grief did not fit patterns well-known to me, challenged my previously unrecognized belief or

assumption about grief, that is, that grief involves emotional distress. In coming to understand her experiences, I was compelled to be truly open to all of the variations in bereavement experiences presented in the data.

Ethical and Human Rights Considerations

Due to the in-depth, unstructured nature of qualitative research, ethical considerations are particularly important in qualitative studies (Ritchie & Lewis, 2003). In this study, ethics and human rights considerations included informed consent, confidentiality, and vulnerability of the population. Ethical approval was granted by the Joint University of Victoria/Vancouver Island Health Authority Human Research Ethics Board. Permission to recruit was granted by the VHS Director of Research & Development and the Manager of Psychosocial Services.

Informed Consent

Informed consent means that potential participants have detailed information about the purpose and procedures of the study in order to understand what participation includes. Risks, potential benefits, and any compensation related to the study are explained. Informed consent is also an ongoing process of ensuring that participants understand that their participation is voluntary and that they may refuse to answer any questions or may withdraw from the study at any time without consequence or explanation. Written informed consent was obtained from all participants in both the individual interviews and the focus group. All participants were informed that the interviews or group would be recorded and transcribed. To ensure informed consent for individual interviews, first, the invitation letter (Appendix B) introduced the purpose and nature of the study and encouraged interested individuals to seek further information. It made clear that participation in the study was entirely voluntary and

confidential. Second, if an appointment was made, the voluntary nature of participation was reviewed and the consent form (Appendix E) was introduced and explained at that time. A copy of this document was left with the participant as their record of the agreement between the researcher and participant. Focus group participants also received a letter of invitation prior to the group informing them of the purpose and nature of the study and inviting them to participate. The consent form (Appendix E) and voluntary participation were reviewed at the beginning of the focus group, questions answered, and copies of the form given to participants for their own records.

Confidentiality

Confidentiality was preserved in all cases. Confidentiality guaranteed that no identifying information pertaining to participants would be available to anyone other than members of my supervisory committee and me. The participants were assigned a number and only I had access to the cross-referenced list of the participants' names. Demographic information was identified by the assigned number only. Names did not appear on interview tapes or transcripts and any references in the interviews that might identify an individual were changed or deleted. All documents and tapes were kept in locked cabinets. Information about who would see the transcripts of the interviews and the group was included in the consent forms. Participants were informed that confidentiality also ensured that no identifying information about individual participants would be revealed in the study findings or any published reports from the study.

Vulnerability of the Population

Given the vulnerable nature of the population being studied, prior to beginning interviews, I considered what to do if a FCG appeared upset by participation in the study.

Many of the participants spoke with strong emotion or cried during the interview. When this occurred, I paused immediately and waited for the participant to regain composure. I offered to take a break if it would help the participant. Also, I made it clear that we could stop the research interview and continue at another time, if they wished, or we could terminate the interview process completely. None of the participants felt a need to do this and they were able to continue with the interview. I did not need to encourage them to seek help from the referring counsellor or nurse or to give them a list of local bereavement support resources. Most of the participants were well informed about such resources.

Limitations of the Study

My inexperience as a principal investigator may be a limitation of the study. Sample size is not a concern in qualitative research design as it is “ultimately a matter of judgement and experience in evaluating the quality of information collected” (Sandelowski, 1995, p. 183). An adequate sample size, according to Sandelowski (1995), is large enough to provide a solid basis for the intended product and small enough to allow detailed analysis of the data. My experience as a bereavement counsellor assisted me in listening to bereaved FCGs tell the stories of their experiences. The resulting data were deep and detailed and permitted a rich description of FCGs’ experiences. The individual interview sample was 11 bereaved FCGs. The focus group size of 8 participants did provide variation and congruence in responses to the presentation of study findings. However, the sample size in this study is small and, thus, limits the extent of the implications that can be drawn from the findings.

Potential Significance of the Study

Many research studies have considered the effects of bereavement variables on bereavement outcomes. The findings from this study are aimed at making a contribution

toward extending knowledge related to FCGs in hospice palliative care, their bereavement experiences, and the effects of these experiences on adjustment to the loss of a significant person. This study provides insight into what bereaved FCGs with uncomplicated grief identify as helpful and as challenging as they adjust to the loss of the person for whom they were caring. This knowledge may add to the understanding of influences on adjustment in bereavement and it could extend current understanding of uncomplicated grief.

Family caregivers in hospice palliative care are among those who use bereavement care services, yet there is little empirical knowledge to guide health care professionals in responding to the needs of this group. Foundational information is necessary for planning health care strategies that effectively support bereaved FCGs and reduce the physical, mental, and social health risks associated with caregiving and bereavement. The findings of this study are intended to help health care professionals to understand the experiences of bereaved FCGs. Further, an interpretive description of what FCGs find helpful in bereavement adjustment may also provide clinical knowledge related to how health care professionals can respond to these FCGs to make a difference. Knowledge gained from this study may help to answer questions about the needs of those with uncomplicated grief and to determine optimal bereavement care strategies to improve the quality of life for bereaved FCGs. Family caregivers themselves may benefit from an understanding of the experiences of other people in similar circumstances and knowledge of what challenges they faced and what has helped them to adjust in their bereavement.

CHAPTER 4

Findings

This study describes the bereavement experiences of eleven FCGs with uncomplicated grief and the helpful and challenging aspects of their experiences that influenced their adjustment in bereavement. Each of the FCGs in this study had cared for someone whom they loved dearly and had known for many years. During caregiving, these FCGs experienced increased intimacy and intensity in their relationships with the dying person. The death of the person was a major loss in each case. As well, nearly half of the FCGs had experienced the death of one or more other close family members within two years of the loss that was the focus of their research interview. The FCGs had been a caregiver in most of these situations also. Approximately one third of the FCGs had a history of depression or were treated for a period of depression following the death of the cared-for person. These FCGs were experiencing uncomplicated or normal grief, but their grief responses were profound and their personal situations complex.

To place the study findings into a broader context, I will first describe the FCGs' experiences of change and loss. I will then discuss three main themes arising from my analysis including (a) FCGs' experiences of the impact of the loss, (b) needing a safe community in which to grieve, and (c) active engagement in adjusting. The first theme describes the FCGs' *experiences of the impact of loss*, including the magnitude of changes in the FCGs' lives following the death, the loss of the connection with the cared-for person, and the personal changes for the FCGs, such as shifts in identity and facing unfamiliar responsibilities, choices, and decisions. The second theme, *needing a safe community in which to grieve*, describes the challenges of support in bereavement, social

expectations related to grief and bereavement, and the beneficial aspects of a safe community for FCGs. The third theme describes how FCGs were *actively engaged in adjusting* in bereavement through the use of memories and remembering, developing a different connection with the person who died, striving for balance, appreciating the good in life, and awareness of personal growth. These themes represent aspects of FCGs' bereavement experiences that are interwoven and concurrent. No linearity of the themes and subthemes is intended except where specifically mentioned.

Family Caregivers' Experiences of the Impact of Loss

The participants in this study shared their personal stories and described the intensity of their experiences. During the interviews, they cried and they laughed; they told intimate stories about the person who died and about themselves. These FCGs were thoughtful and eloquent in relating their bereavement experiences. Their lives had changed fundamentally. They had suffered and some of them still suffered at the time of the interview. The person who died continued to be missed and remembered for years after they died. The FCGs' sense of identity had been shaken but they managed gradually to rebuild self-confidence and find meaning and purpose amid loss and change.

This section describes the changes that FCGs experienced following the death of the cared-for person and the impact of these changes for them. There are three main themes here. First, the *magnitude of changes* in the FCGs' lives describes how they responded to changes that occurred because of the death of the cared-for person, to whom the FCG was so close. Second, the *loss of connection* with the person who died, includes the ways in which FCGs missed them and the connection between that person and the FCG. Third, in describing the *personal changes* they experienced, the FCGs spoke about

struggling with shifts in their identity, wondering about the meaning and purpose of their lives, and facing unfamiliar responsibilities and decision making.

Magnitude of Changes in the Family Caregiver's Life

The FCGs reported a myriad of changes in their lives after the death of the person for whom they had cared that could be overwhelming for them. Some FCGs spoke about how hard it was to realize that the changes were forever and that life would never be the same. They described their experiences of loss as having “lost everything,” experiencing “a total change in [their] world,” and realizing “life is changed forever.” One husband reported, after his wife died, that, “Everywhere I went, there’s a vacant place.” One widow described herself as panic-stricken by all the changes in her life. Because she felt overwhelmed, she said, “I had this incredible sense of urgency that I had to hunker down, waiting for the siege.” As a consequence, in the first year of her bereavement, she had done “silly things” on impulse, spending money to try to feel more secure. Because there was such a big hole in her life following her husband’s death, another woman said, “It was just like my life fell apart... and I just wanted to scream.” One daughter, whose parents died, said that she not only grieved for her parents but also for the many changes that followed from their deaths. She clearly described how her “carefree” life and her relationships with others had changed:

I grieved having a bit of a carefree type life, and now it was different. When [my] siblings would have struggles, we were getting the two in the morning phone calls that my parents would have gotten. So I grieved that again, the new heightened responsibility [for my siblings]. I grieved that things would never be the same. I grieved that we wouldn’t be able to go back to the house and just hang out or have Christmases there or do whatever. I think there’s a sense of it being permanent after somebody dies that no matter what, you can never be the same anymore. It will never be the same. It changed my

relationship with my siblings. It changed my relationship with my husband, even for my children ... I definitely feel like I have a different life. And that was part of my rage; I didn't want it to be. It's not fair. I didn't pick it. Why does it have to change?

Other FCGs concurred with these types of responses following the death saying that they had a new and different life in which they had to "survive."

Even though they faced such a magnitude of change, most of the FCGs were aware of a need to get through it and that life goes on. One man said that he knew "there was a light at the end of the tunnel" and this helped him to be patient with himself. He also spoke about facing the changes in his life as an obligation:

It's a new life. It's a new chapter. I thought: we have an obligation to life and to live. And it's difficult, sometimes very difficult, but it's an obligation. I like to think that I take it seriously. And I wanted to use [my] experience over the past two years [of caregiving] to get the most out of it because it was extraordinary.

A daughter, whose mother died, said that knowing that life goes on had a big influence on her ability to get by day-to-day. For many FCGs, dealing with the magnitude of change in their lives was emotional, exhausting, and challenged their adjusting in bereavement.

However, it seemed that they also had trust in themselves and in the process of adjustment.

Loss of Connection with the Person who Died

In this section, I describe this loss of connection and how FCGs experienced it through missing the person who died. Missing had several facets including; continuing to miss the person despite the passage of time, the close connection between missing and remembering, dealing with meaningful dates, and a future orientation to missing the person who died. Family caregivers described a deep, intense, personal awareness of the loss of their connection with the person who died that permeated many aspects of their

lives, often for extended periods of time. In describing their experiences of the loss of connection, FCGs used expressions such as being “left alone,” and “a huge hole” where the person who died used to be. They experienced sadness and loneliness and they cried and cried. One man said that although he was surrounded by friends, he was feeling the emptiness of his home and “the aloneness of life.” Another man said that he still thought of his wife and felt sad every day. Some FCGs also experienced anger, restlessness, and depression. Several FCGs were angry that such a loss could occur. Two sisters were angry at God for letting such a terrible thing as the death of their parents happen. In describing the impact of the loss of connection with her husband, one widow described how devastated she was and how restless she felt:

I could not concentrate on anything. There was such a big hole and so much missing that I just kind of wandered. I wandered in the evenings so much. I found it really very hard. It was just the loss of the connection between the two of us that was so horrific, and still is today.

Another FCG said that “it is overwhelming... when you lose somebody that you loved so much.”

Missing the person who died.

Family caregivers spoke about how they *continued to miss the person* despite the amount of time that had passed since the death. Missing the care-for person was closely linked to remembering them, especially in the first months of bereavement. Certain times or meaningful dates were challenging for FCGs as they could precipitate intense missing. Missing the person who died sometimes also had a future orientation for FCGs.

All of the FCGs said that they continued to miss the person who had died, despite the length of time that they may have been bereaved. Some FCGs longed for the love and closeness of the relationship and missed the special nature of that connection. A widow

longed for the comfort, acceptance, and validation that she had felt with her husband.

Another FCG missed the ease of familiarity within the relationship. He spoke about the shared history and intimate knowing of a loving partnership, calling it “complicity.” One woman, whose brother had died, missed this life-long connection and all the things they had done together growing up and as adults. She felt she was losing her best friend as well as sibling.

Continuing to miss the person who had died happened in a number of ways. For example, the person who died was missed as a family member. Family gatherings were challenging for one daughter because getting together with family made her more aware of missing her mother. In her words, “I love, obviously, seeing people [cousins and family friends] and their mothers but at the same time I absolutely hated it.” One FCG missed her parents as leaders in the family and felt awkward being the senior generation and matriarch of the family now. Many of the FCGs missed the person who died in their familiar roles and for their contributions to daily life. One woman described how she missed her husband: “It’s the sharing that you miss so much. That’s what I really miss. It’s the sharing of mundane things.” The loss of day-to-day shared habits made FCGs very aware of missing their connection with the person who had died.

For all of the FCGs in this study, missing the person who died seemed to be closely linked with remembering them. For a period following the death, *missing and remembering* appeared to be concurrent, intense, and painful experiences. In explaining how memories triggered his grief, a husband said: “It’s like living life through a veil of tears in that initial period because everywhere I went, wherever I looked, there were places we’d been, things we’d done, things we’d shared.” In this period, remembering

included thoughts and images of the person who died and their illness and dying. Several FCGs reported that they only remembered the person as sick for a long time. One daughter said that these memories, although painful, were important to her and helped her to accept the fact that her mother had died:

The first year, that was all I remembered about her [mother] was her being really sick ... all I could remember was that being really sick, and looking really sick, and sounding really sick. I couldn't remember her healthy. Those thoughts were preventing that [remembering her healthy] but ... I needed to think those [thoughts about her being sick]. It was the only way that I'd be able to accept her death was to remember and to know that she needed to die. Otherwise, I wouldn't have been able to accept it.

Some FCGs related vivid recollections of the illness and death after several years had passed, perhaps indicating the deep impression these experiences had created. One widow recalled the last two days of her husband's life in poignant detail although that had been three years earlier.

Meaningful dates, such as birthdays, holidays, Mother's and Father's Days, and the anniversary of the death date also reminded FCGs of how much they missed the person who had died. One FCG echoed the experiences of others when she said, "My first birthday was horrible. His birthday was horrible. Yeah, Christmas. That first Christmas that we had without him was not good." In speaking of the anniversary of the death, some FCGs reported that they began to think about this and grieve for the person who died before the actual day. One widow felt that the whole month in which the death had occurred was terrible. For another widow, strong anticipatory feelings about the first anniversary of her husband's death happened in advance of the actual date:

The week before his [first] anniversary, I had a meltdown. And I got out all my love letters and I was going through papers and I just wept all day long. I had just a dreadful time. But it was the week before.

A daughter related that her family no longer focussed on the date of her father's death and, for the first time, had not gathered on the fourth anniversary. The family did continue to acknowledge other important dates such as their father's birthday. Another daughter, who had a number of losses, said that she did not focus on these kinds of dates at all and had to look up the date of her mother's death for the interview.

Missing the person who had died sometimes had a *future orientation*, especially for younger FCG participants. These FCGs wished for the presence of the person who died in relation to life events and transitions. One young woman explained how she missed her parents:

When they [parents] died, there was a loss of them, but it was also a loss of future events. As I'm now stepping into [a new] role ... I really wish that my mom were here to help me figure out what the heck is going on. I think that's going to happen because of all the rest of the big life events that will happen in your life.

Facing her future without her mother, a young woman said that she almost dreaded things that she also looked forward to. Younger FCGs anticipated missing the person when important events, such as marriages, births, or graduations, would occur. These FCGs wished that the person who died could participate in special family events. In speaking about a family celebration, one daughter said, "They [parents] would have loved that." Another daughter spoke about her anger connected with the future her parents would miss:

I felt gypped by a lot. I felt gypped, both for me in my life and for them [parents] as well. They raised their kids and did all the hard part and then finally got to the grandparent, kids-out-of-the-house stage and are not around to enjoy it. So I would say I felt gypped.

Another daughter anticipated missing her father in difficult times that might lie ahead, such as relationship problems or sickness in the family. One woman said that she missed

her parents not only for herself but also for her children who would not have grandparents “there just to love and spoil ... my kids.”

Missing the person who died seemed to be a central grief experience for the participants. They missed the care-for person deeply and continued to miss them years later. Remembering the person who died could intensify FCGs’ feelings of missing that person, most frequently in the early months of bereavement. Dates that held special meaning for the FCGs in terms of the person who died could trigger strong feelings of missing. Missing the person who died did not just happen in the FCGs’ present as they anticipated missing them in the future.

Personal Changes for the Family Caregiver

Along with the many changes in their lives and the loss of connection with the person who died, bereaved FCGs experienced changes in themselves and in their daily lives. They struggled with finding meaning in their situations and with shifts in their identity that were distressing to varying degrees. Bereaved FCGs were also confronted with unfamiliar responsibilities and responsibilities that were previously shared. They had to make choices and decisions about many areas of their lives, from major life decisions to personal goals to daily routines and habits. These personal changes presented further challenges in conjunction with the global changes and loss of connection following the death of the cared-for person.

Struggling with shifts in identity.

Many of the FCGs were aware of and distressed by shifts in their personal identity, that is, their sense of themselves as individuals and of their own lives. They questioned the meaning and purpose of their lives. While struggling with their sense of

identity, many FCGs felt vulnerable and their self-confidence was shaken. One widow described how she felt about the changes within herself:

As I said to a friend this morning, it's trying to learn to live in my own skin. It's a new skin. I mean I lived in the other skin quite happily. It's as though you don't know yourself as a person. You don't know who this person is ... I guess it's like a butterfly - metamorphosis - you're coming out of a cocoon or something. That makes it sound better than it feels!

Some FCGs acquired new roles such as, widow/widower, single person, or orphan and wondered what this meant for them personally and how they could adjust to this new person they had become.

Family caregivers realized that the meaning and purpose of their lives had changed “drastically” and would continue to change. Some FCGs spoke about how caring for the person who died had been their life purpose and now that was gone. Many FCGs struggled with questions about their purpose and what to do with their lives. Such questions troubled a bereaved husband who wondered “Is anything worthwhile?” and was apprehensive about whether this situation would get better or not. Another FCG felt that nothing mattered and nobody cared. A retired man, whose wife died, identified his need for a purpose or a “destination” because:

We'd been married [over 40] years and we went places and did things individually but still within the context of our plans. And then suddenly, well, what's my plan? What's my purpose? And that was a very different thing for me to start looking at and trying to settle in to that new mode... It was more of an experience of I can't see a destination. I can't see what next ... I'm talking about life today, or tomorrow, or next week. Not only where am I going, but how do I get there when I don't have the energy? There's just so much missing that I needed to get on with life.

Family caregivers were at various places concerning their purpose and their identity. A daughter felt that having been with her father throughout his illness, “from the beginning to the end,” helped her in putting together pieces of her life’s meaning and purpose. One man said it took his wife’s death “for me to start to think about what it all means. What’s the purpose? ...What am I going to do with the rest of my life?” Although it “took a lot of adjusting,” some FCGs felt that they were making their way and settling into their own lives.

Facing unfamiliar responsibilities, choices, and decisions.

Because life was so changed and the person who died was not there, FCGs were faced with many new and unfamiliar choices and decisions. Many of them also took on new responsibilities. Often FCGs were taking on certain responsibilities that had belonged to the person who died. These new responsibilities were not always welcome acquisitions nor were they easy adjustments. Some FCGs who had lost a spouse or partner felt anger and resentment at having all the responsibilities for the house and the garden. Although she was a competent professional, one widow felt abandoned and burdened with responsibility. She wondered, “Who will care for me now?” A daughter, whose parents died, worried about her ability to fulfill a parenting role with her younger siblings. She counted on them, as young adults, to sift through her advice thus lightening her sense of responsibility.

Choices and decisions were challenging parts of bereavement for FCGs in a variety of ways. One FCG spoke about the unfamiliarity of decision making and how “we hadn’t been put in [this decision-making] situation before.” A woman said that it was realistic and important for her to learn to plan and make life decisions but she found

herself still thinking in the shortened time frame that had been necessary during caregiving for her mother. One man started out choosing small short-term goals, like sleeping through the night, and gradually moved toward larger longer-term goals, like beginning the writing of a book. A widow reported that the demands to make decisions were constant, but, over time, she began to develop a new attitude toward making decisions and choices:

So you begin to learn, you figure, it's required to make choices - that you are making choices; that you have this freedom; you have these options to make, to do, to try things out.

Some FCGs faced choices and decisions about simple tasks and habits, such as looking after oneself. Having cared for a dying loved one, some FCGs realized they were exhausted and it was time to take notice of their health and well-being. One man who had been a caregiver for many months decided he needed to look after himself better:

I ... still consciously remember saying to myself, "You are exhausted! It's about time you started recognizing that, taking notice."... I know that that was a turning point for me, to recognize that yes, I was exhausted and I needed to start looking after myself a little better, i.e., more nourishing meals for one thing, and getting back into exercising.

A widow knew she had to take care of herself but putting herself first was "alien." Family caregivers had to make decisions about what to do to establish new routines. Some FCGs tried new things, sometimes trying and dropping a number of activities, sometimes finding new hobbies and connections. The freedom to make choices could be uncomfortable. One woman was eloquent about how she experienced her choices as somewhat overwhelming:

I guess that's what it is - I'm trying out life again, trying out new ways of living. And I've got this ruddy smorgasbord! Your life before that

was planned – it was a menu [and] you knew what was going on. Now you've got this smorgasbord.

Personal changes for the FCGs presented challenges in several areas. Bereaved FCGs experienced changes in themselves as distressing shifts in their identity. Choices and decisions often felt constant and ranged from day-to-day decisions to major life decisions.

To summarize, the impact of the loss of the cared-for person was experienced as a whole host of challenges that were exhausting and demanding for FCGs. They described intense individual reactions to the changes brought about by the death of, and loss of connection with, that person. These changes pervaded many aspects of FCGs' lives and affected them for years as they continued to miss and remember the person who had died. Family caregivers reported that they sometimes felt overwhelmed and had concerns about their ability to adjust in bereavement. However, they also reported times when they trusted that they could manage and would adjust.

Needing a Safe Community in which to Grieve

Grief and adjustment in bereavement occurred in a social context that included the community of relationships within which FCGs lived. Because of the pain of the loss of connection to the person who died and the intensity of grief, FCGs felt the need for safety, comfort, and understanding from the people around them. All of the FCGs had and/or found a community of support but they also faced challenges in terms of support from certain family members, friends, and acquaintances, and from society in general. These FCGs talked about wanting to be accepted but sometimes received misguided offers of support. The FCGs also encountered social expectations that were sometimes

difficult to deal with. When they found a safe community in which to grieve, FCGs described this as highly beneficial to their overall adjustment to the loss.

The Challenges of a Supportive Community in Bereavement

Family caregivers spoke about the challenges of support in bereavement from two perspectives. One perspective was that FCGs wanted the acceptance and support of those around them. The other was that they encountered misguided support efforts offered by family, friends, and others. Many FCGs experienced both of these challenges.

Wanting to be accepted.

Many FCGs reported wanting to be accepted by the people around them. Some FCGs wanted acknowledgment of the changes in their lives and in themselves. For instance, one woman wanted acceptance of her response to a family health crisis. She wanted her friends and family to understand how the death of both her parents influenced her need to prepare for the worst rather than think positively.

Other FCGs longed for their intense grief to be accepted and allowed to be what it was. A daughter who had cared for her mother made her desire to be accepted clear:

It's just I'm so different from so many people that I want someone to say, "I realize that I don't have the same situation as you. But I also realize ... that this just sucks! This is so awful! And I get it." It's just that - allowing me ... to just be up and down and confused. That this is the process. Not making me feel bad for it, not making me feel stupid, or not making me feel like, "Okay, she's been gone 3 months, back to normal."

For more than half of the FCGs, wanting to be accepted seemed to be a challenging experience. Sometimes, FCGs experienced stress in relationships when acceptance was lacking. Two married women each wanted their husbands to accept their highs and lows and struggles to grieve and adjust in bereavement. These women said that, although their husbands tried hard to be supportive, neither had any significant loss

experience to inform their efforts, so there was “an element of grief they just didn’t get.” One woman admitted that this was hard on her marriage. Some FCGs wanted acceptance and reassurance where it was not forthcoming. One widow was seeking reassurance from her friends but she did not receive it and became disappointed. She began to blame herself and doubt the value of her longstanding friendships.

The younger FCGs often felt isolated from their peers. They spoke about having few or no friends with similar losses. Their friends were busy with things that are typical in young people’s lives. As one daughter said, “That wasn’t where I was at.” Another young FCG wanted friends to be more in tune with and accepting of her grief and what was important to her. She was irritated with them for not understanding what it was like to lose a parent. Some FCGs wanted to be known and accepted in their workplace or in their church community. For instance, one woman wanted the people in her new church “to know who I am today because of where I’ve been and I wish that they knew so that they could put the pieces together” and be more accepting of her. In response to these challenges, these FCGs felt isolated and misunderstood, which was unhelpful in their adjustment in bereavement.

Misguided offers of support.

Many FCGs reported that extended family, friends, and acquaintances could be misguided in offers of support. While FCGs acknowledged these people as well-meaning, they did not always find them particularly helpful. Sometimes people assumed that they knew how the FCG felt or they offered clichés. One daughter complained about the platitudes that she heard, saying, “People say some things that they are hoping are helpful that are just dumb ... Their intentions must be good but I don’t know where that would

come from.” For example, she and other FCGs were advised that they should take comfort because “the person who died was in a better place,” “at least the person was no longer in pain,” and “God takes the best.” One woman who had cared for her brother found certain people unhelpful when they asked about everyone else in the family except her. A young FCG experienced what she called “overbearing support,” when someone asked her too frequently how she was doing. At the same time, she explained the paradoxical nature of the dilemma it created for her in getting support when she did need it:

Don't ask me 17 times a day and put your hand on me and say, “How are you doing?” and you say you're fine and then, “But really?” ... [That] makes me not want to be around this person as much ... And then if I do open up to them at one point and say, "Oh yeah, I am having a hard time," they continue to act like that [offering overbearing support]. So I just want to continually let this person know I'm fine, I'm fine, I'm fine, I'm fine, I'm fine ... You'd like to be able to open up to this person because you know they're there for you and that they're being supportive because they care. But I feel like I don't ... want to break down this wall because then you're back at step one ... [When you] let everyone believe that you're fine all the time, they stop worrying about you. But then, when you are having a down time, you don't know who to turn to because you promised all these people you were fine.

The reactions of FCGs to well-intentioned but misguided efforts at providing support included feeling angry, ignored, and unsupported.

Not all FCGs experienced others as well-intentioned. For example, one daughter said that certain people offered support with an attitude that she read as, “Well, I asked how she was doing, so I can check that off my list of things to do and feel good about myself for another thing.” The FCG experienced these offers of support as insincere. It seemed that what other people expected to be helpful did not always have the intended result.

Encountering Social Expectations about Grief and Bereavement

Family caregivers reported encountering social expectations such as bereaved individuals will conform to certain social norms, based on common understandings of grief and bereavement. Generally, these expectations informed beliefs about how the FCG should grieve or misconceptions about grief. Social expectations influenced other people, FCGs themselves, and the interactions between them. Many FCGs viewed these expectations as challenging.

These FCGs said that common social expectations were often imbued with the work of Elizabeth Kubler-Ross, which has become imbedded in North American culture. Family caregivers were offered advice about Kubler-Ross's five stages of grief (denial, bargaining, anger, depression, and acceptance) and also found these in books. One daughter said it was easy to get caught up in thinking about what she should be doing or feeling and when. A book on grief suggested she should feel one thing and then another and so on. This information did not fit her experience and she wondered, "What if ... you're all over the map?"

Sometimes FCGs encountered beliefs about the right way to grieve that contradicted their experience. As a result, some FCGs judged themselves or felt judged and misunderstood by others. For instance, one daughter was irritated when people, who had not been bereaved and she felt could not understand, talked to her about what she should and shouldn't feel.

Several FCGs encountered social expectations about the importance of dealing with grief right away. One FCG internalized these expectations and worried about her adjustment until she was able to get reassurance:

Everybody would say ... that the [grief] feelings come so that we can deal with them because, if you don't, down the road it will come back and it will be worse. But because I was knee-deep in stuff, and life, and family, I didn't. So I actually worried about this. Worried that maybe it would come out at some future time, that I'd be sitting at dinner and all of a sudden break down or something. So [I asked] ... a counsellor ... I said, 'Am I a ticking time bomb?' And he said, 'No, it's just a process.' So then I took the pressure off that I needed to figure out how to cry or I needed to figure out how to process that.

Misconceptions about grief conveyed messages to FCGs that grief was finite and short and that they should not grieve openly. They faced various expectations about when they should be finished grieving. One widow's friends suggested she needed to get help to "snap out of it." She reported her friends' expectations and lack of understanding:

I just didn't feel they [friends] were very supportive.[They were] very happy to tell me "How well you're doing and I'm surprised at how well you're doing, you're doing so well." What's doing so well? I mean I can put on a really good front. Is that what it is? And people, they don't want to hear that you're sad. Nobody's interested. They want you to be happy. That you're getting on with things. They don't want to hear that you miss him [husband]. They don't want to hear. They don't want to talk about it.

Other FCGs reported being told to "get on with it" or to "buck up." A few FCGs told about showing their grief and having other people tell them that they were "making a production" or that talking was "just prolonging it." These kinds of expectations demonstrated a lack of understanding of the complex and individual nature of the grief process that FCGs found distressing. One man complained that his brother made "idiotic comments" saying that "where he [brother] came from, people didn't grieve" and the FCG should just "get on with his life." These situations often created stress in the relationship between the FCG and another person and could lead to anger. Faced with such advice, some FCGs stopped talking about their grief.

In these ways, social expectations often affected the quality of the support offered to FCGs and presented challenges to their adjustment in bereavement. The challenging aspects of wanting to be accepted, encountering social expectations, and misguided support seemed to conjoin to produce a wish in FCGs to be able to express their grief in a safe community with people who would listen and understand.

Components of a Safe Community in which to Grieve

It was important for FCGs to feel comfortable and safe within their community of support. Feeling validated and justified in their grieving were key aspects of a safe community. Family caregivers' perceptions about the safety of their support community also seemed to be shaped by the quality of relationships and/or a common background of experience.

Feeling validated and justified.

One of the FCGs summarized what she wanted from her support community saying, "I think just everybody wants to feel validated and justified and told it's okay." Validation was a term that several FCGs used that captured the desire for their experience to be accepted as what would be considered "normal." They explained that validation meant being heard by someone who cared, comforted that it was okay to feel the way they did, and reassured that they were on the right track. Family caregivers felt validated when others were knowledgeable and understanding about grief. A daughter explained the importance of validation for her:

If you've never gone through it before [losing a family member], you're not sure what to expect. "Is this okay? Am I going on too long? Am I doing this too much? Am I doing this too little? But this is not me." When you read about it or talk to other people [who have knowledge or experience] about it, you go, "I guess I'm in the normal range or whatever." Not that there's a normal range for grief, I

think. But, I think it gives you that, “I’m okay. I’m in the clear. I’m not going off the end of the spectrum here.”

Family, friends, and other bereaved people contributed to FCGs’ sense of validation through their acceptance and understanding. The sincerity of their caring was evident to FCGs. Validation was provided by professional helpers, also, such as the FCGs’ spiritual leader, counsellor, and family physician. The professional help offered was generally appreciated by FCGs. Good information about grief from a counsellor helped several FCGs with worries and concerns about their grief and adjustment. Some FCGs said that, in a safe situation such as a formal bereavement support group, witnessing other people’s grief was validating. While support groups did not suit all of the FCGs who tried them, other FCGs agreed that it helped to know that other people hurt as badly as they did. One FCG appreciated an opportunity to be with bereaved people who were suffering because “one of the really helpful things is when you realize the way you’re feeling is the way people feel when they’re grieving.” These sources of validation offered encouragement and reassurance that the FCGs were okay as they were.

Some FCGs said that when they felt validated, this justified the feelings they were having. One man, for example, felt justified when he realized that he should feel the way he did about his wife’s death because it was a reflection of their love. FCGs spoke about the comfort they got from finding it was all right to be angry and to know it was “okay to be not okay.” Being able to track their progress against the progress of others and talk about the similarities and differences in feelings helped FCGs to feel justified in their grief. Through experiences of being validated and justified, FCGS came to have a better understanding of grief for themselves which helped them in adjusting in bereavement.

The quality of the relationships.

The quality of the relationships that FCGs had with people defined the safe community in which they could grieve. They found the warmth and acceptance that they wanted in a variety of relationships, such as with friends, in their families, and from caring professionals. Some FCGs said that they felt comfortable with people who were there consistently. For example, because of misguided support efforts, one woman became used to saying she was fine and keeping people other than family at a distance. When she realized that some friends were genuinely and consistently caring, her trust with them began to develop.

For several FCGs, there was nothing that compared to the safety and support they felt with family. One woman said this was because, “We have strength in each other,” and, in speaking of her siblings, a daughter said, “We’re the core.” The quality of relationships with professionals varied. For one widow, her minister was a central pillar in her support community but another FCG found that she did not get very skilled or knowledgeable grief support from her pastor. A widower felt that his doctor was especially helpful with reassurance about the caregiving he provided for his wife and an offer of ongoing availability. In contrast, for one woman, the callousness of her family physician’s initial jocular approach to her about her bereavement left her feeling angry with him.

Family caregivers spoke about appreciating people who offered warmth and understanding and accepted grieving as natural. For example, one young FCG, whose mother died, found the middle-aged women in her workplace especially warm and kind and that they “remind me of my Mom.” All of the FCGs particularly valued the comfort

that supportive people gave them. One man was touched that his neighbours reached out to help him by cutting his lawn when he was not able to, leaving muffins on his doorstep, and connecting with him more frequently. These acts of kindness strengthened his sense of being accepted by those around him. Several FCGs mentioned closeness and strengthened ties in their relationships with the people in their support network who were trustworthy, available, and caring.

Sharing a common experience with another.

Another component that constituted a safe community in which to grieve included sharing the experience with others who knew the person who had died or with those who had also been through the caregiving process and had lost a loved one. Family caregivers reported a special connection with those people who shared the FCGs' history; they felt comfortable with people who had known the person who died. Where family and friends had been together through caregiving and the death, FCGs felt that this was an important bond that helped FCGs, friends, and family to be there for each other in bereavement.

One FCG appreciated the experiences shared within his family:

They [the adult children] were bereaved too. They needed my support as much as I needed theirs. So it really was an experience that none of us would have opted for but which, as a family looking back on it, we all appreciate in terms of the way in which we could be so close to each other during those times.

Some FCGs said that, because of shared history and experiences, they found a stable connection "no matter what" with family members.

Sharing a common experience with another occurred in relationships with other bereaved people. Several FCGs mentioned friends with similar losses. One woman said that she had a couple of friends in similar circumstances and she could always talk to them. Formal groups and classes for bereaved people, facilitated by professionals or

trained volunteers, were valued by many FCGs because they were “all in the same situation.” FCGs spoke about a bond or warmth that existed because of the shared experiences of bereavement among them. Another FCG said that when bereaved people are together there is a “wealth of information” and practical knowledge to call upon. This same FCG said that bereaved people had compassion for and could help each other. Other FCGs mentioned picking up suggestions and “strategies for coping” that were helpful. They said that discussing mutual issues and exchanging ideas helped them to manage grief and day-to-day living. One FCG said, “I couldn’t say enough about the benefit of that [bereavement] group.” Several FCGs reported that they had made some “really good friends” from the bereavement groups that they attended. In contrast, one FCG did not continue with a group where others’ experiences were different than his.

A few FCGs mentioned that stories of other bereaved people that they found in books on grief and loss were a source of information and comfort to them. One woman with several losses explained how reading about another’s grief helped her to understand her own grief:

Just [reading] books on loss. How different people have dealt with loss and how not everybody deals with loss the same way ... Not every death is the same or is the same for every person ... And how you feel about those and how you grieve for those people or grieve for the loss of that person is totally different ... To be able to pick up a book and read that somebody else had the same kind of circumstances and how they dealt with it and how you deal with it or have dealt with it was interesting as well as beneficial.

One daughter was glad to find a series of books specifically about the loss of one’s mother. She said that the stories and information in other books that she read did not seem “very accurate or relatable.” Stories about how other bereaved people managed,

whether in books, in a group, or from family and friends, offered a sense of encouragement that these FCG could manage, too.

In summary, when FCGs were able to find a safe community in which to grieve it seemed to help them see their grief and adjustment as natural. Within a safe circle of people, FCGs could talk about the person who died and share their pain if they wanted to. One woman said, “I find it safe with them [family and family friends] because I feel that I don’t have to explain everything. I don’t feel [like] a weirdo for the way that I feel.” Another woman said that she gathered strength from the caring people around her. In a safe environment, FCGs said they could speak frankly and express emotions. Some FCGs said that they could share their grief and cry as much as they needed to cry.

Giving and receiving support in, and encountering social expectations about, grief and bereavement continued to be challenging experiences for FCGs. The people who formed the FCGs’ community of support continued to be very important. Many FCGs spoke about the comfort they got from sharing their experiences, emotions, and thoughts with others who cared. One FCG said that people did not have to say anything profound to be helpful; they just had to listen. In all of the ways described, a safe community of support seemed to help FCGs to adjust in bereavement by lightening the burden of challenges and problems that they faced and providing a caring environment in which to grieve.

Active Engagement in Adjusting

There were several ways in which the FCGs worked towards their own well being and adjustment. In the interviews, several FCGs said that “time heals.” When asked if they thought that there was anything that they did that helped time to heal, the response

was often, “I don’t know.” And yet, in their interviews, these FCGs described many ways in which adjustment was occurring. For example, the interviews highlighted how they mobilized their personal resources and how this was central to adjusting in bereavement. Specifically, FCGs talked about remembering the person who had died, establishing a different kind of connection with the person who had died, striving for balance, appreciating the good in life, and awareness of personal growth, as key factors that were involved in their adjustment process.

Remembering the Person who Died

Remembering the person who died could be a painful reminder for FCGs of their loss of the connection with that person. However, it seemed that memories of the person could also comfort FCGs and assuage the distress of missing that person. *Choosing to remember the good times* and appreciating the past helped FCGS to handle the pain of missing the person who died. For instance, one woman choose good memories because she “didn’t want to focus on things that were going to bring back unhappy memories.” A wife noted that when difficult emotions arose, she thought about positive times that she had shared with her husband. She said, “When I’m missing [him], I think about [a time that] was just so fantastic,” and that she could live on the “super” memories she had. Some FCGs found that memories of a loving relationship nurtured them. Many of these FCGs had memories of good times during their caregiving experiences, times of closeness and enjoyment. One man said it was part of his satisfaction to remember that he was able to help his wife accomplish the things that she wanted to do before she died. Because they had good memories of having taken care of the person who died, these FCGs reported that they had no regrets.

For many of the FCGs, *sharing memories* of the person who had died was also helpful. Sharing memories provided mutual support and comfort for family and others who had known that person. For instance, one daughter found that going with her siblings to put flowers on their father's grave created a time to reminisce and was a helpful strategy in adjusting in their bereavement. One widow visited with her husband's family and enjoyed hearing their stories about her husband's life before she knew him. Sharing memories and the emotions connected with them also had bittersweet aspects, as this FCG recounted:

I took [the video of my wife taken during her illness] with me at Christmas time and the evening of Christmas Day, I said, "Let's just watch that together." Well, it was very, very moving for all of us, especially [our adult] kids.

Family caregivers also shared their memories in conversation with people who may not have known the person who died. This kind of sharing was important to one daughter as it "keeps her [mother's] memory alive." Most of the FCGs took the opportunity presented by the interview to relate anecdotes about the person.

Mementos of the person who died also helped FCGs to remember. Some FCGs spoke about keeping mementos, such as cherished possessions, photos, or videos of the person who died, close to them or available. One widower said the house felt less empty when it was filled with the music his wife had loved. Some of the participants, like this woman, shared mementos during the research interview and spoke about her habits of remembering:

I'll just show you, she [my mother] made a book. It's interesting to see. It was one that she filled in that the family got her one year to answer all these questions about her growing up and when she was young. The pictures didn't turn out very well but it's interesting ... I've got her picture up there and she's in all kinds of albums. I don't sleep very well so I'm often up at night and I'll pick up an album and look through it.

Despite the distress that some FCGs felt in remembering the person who had died, all of them were clear that they did not want to forget that person. One man said he would be ashamed of himself if he ever forgot someone as important as his life partner and best friend. Some FCGs suggested that remembering itself was not as difficult as dealing with the emotions that sometimes surfaced when memories arose. As one woman said, “You never want to forget them but you want to be able to in the future think about that person without being emotional every time.”

The emotional impact of remembering the person who died seemed to change over time. For example, a sister who cared for her brother in his home recalled being very aware of the absence of her brother when she visited the home for the first time after his death, stating, “It was very hard... it very much brought it into the forefront, that life has changed once again.” With each subsequent visit, being there got easier for her and, gradually, she began to feel his presence and take comfort in remembering him. Other FCGs also experienced changes in their ability to remember without being “distressed every time.”

Recognizing A Different Connection with the Person who Died

Most of the participants reported that they had some *sense of connection* or continuity with the person who died. This connection seemed to provide a sense of closeness, comfort, and guidance that helped many FCGs in adjusting in bereavement. One daughter explained how she felt her dead father’s presence, “ It was, although a different type of relationship, a very different type of relationship, but that his love and his concern and care weren’t gone.” Other FCGs described experiencing the person’s presence as if that person was close by or as a strong mental sensation. They suggested

that such a presence was comforting and assisted them with managing their own lives. Several FCGs said that, in times of uncertainty, they thought about what the person who had died would advise. For example, one daughter consulted memories of her father for guidance about fulfilling a new role:

As a parent, as I'm stepping into that role, I realized how he [father] did it [parenting], I think I need to be able to rely on some of his past wisdom and try to stay in tune with some connections there.

One wife felt connection with her husband through humour because humour was an important part of who her husband had been. She also spoke about remembering her husband so vividly that she felt like she could almost touch him.

Some FCGs reported that they continued to talk to the person who died. An important connection for one woman was spending time in places that had special meaning in relation to her brother who died:

It makes me feel better. I feel like, even though I know that person [brother] isn't there really, it makes me feel closer to [him]. Yeah, being able to go down there and talk about what's happening ... I just feel like he's there. So I can talk to him.

A daughter said that part of her connection to her father was to have conversations “in my head of what I would say to my dad [and] what he would say to me.”

Honouring the person who died was another way for some FCGs to have a sense of connection. They still wanted the person who died to be proud or pleased with the FCG's present situation or actions. One man said that his wife would be surprised and proud of him for attending a bereavement group. A daughter spoke about honouring her mother by fulfilling some of the dreams her mother had for her:

I still have a need to be the kind of person I would be if she was around. I just want to make her so proud ... Being she was such a role model, I want be like her ... She had dreams for me. She wanted me to do really well. As a specific example, I guess, she always really regretted that she never had her own home,

never bought her own place. So she instilled that into me, invest in a place. And she passed away and I got an inheritance. The only thing I would look at was buy a condo ... It's just all these things that she'd be so thrilled with. She'd get such a kick out of, so I like doing those sorts of things that always will feel that I can [say,] "Look at this!"

Some FCGs longed for a stronger sense of connection than the one that they currently had. One daughter, who had small children, expressed her regret at not having time to feel a connection:

Some people feel closer or still somewhat close to the person after they've passed away. I don't feel that. I don't know if it's because my life is busy right now. I don't have enough time to blow my nose let alone sit down and concentrate and try to feel them. I've always wanted that.

For most of the FCGs, their *personal and religious beliefs* about what happens after someone dies were an integral part of a different connection with the person who died. The common beliefs among FCGs that supported this connection were that the person who died continued to exist somewhere and that the FCG would be reunited with them in an afterlife. For many of these FCGs, their religious faith was the foundation of their beliefs. A few FCGs had individual beliefs about what happens after someone dies or were searching for a personal understanding. Generally, FCGs said that their beliefs and the sense of connection they provided were helpful and comforting to them.

Some FCGs spoke about a continued existence in which the person was healthy, not suffering, and in a better state than they had been in life. This belief gave some of the FCGs peace about their loved one. One daughter was comforted by clear images of her mother. She said, "I envision her skipping through a field of bluebells ... as a young woman and in good health and vibrant and happy. I envision her like that all the time." Although he did not focus on life after death, one widower felt a connection with his wife because he believed in "the indestructibility of the human personality."

A belief in being reunited with the person who died seemed to provide FCGs with hope and to ameliorate the pain of grief. One spouse said it was comforting to know that her husband was in Heaven and she expected to be there one day too. Another woman, who had experienced more than one loss in the family, explained how her beliefs helped her to maintain a sense of connection saying:

There's a belief that there's life after death and that all will continue as it was here with the family unit. So knowing that ... it has been nice because, if I didn't have a belief that there was life after death, it would be very tragic to lose a [family member] because that was that. But, because there's that belief that it's not the end, that I'll see them again, it took away some of that [loneliness].

In contrast, one man was searching for a different understanding as his former beliefs no longer made sense to him. He said, "There has to be more to it than just living your life and dying and then you've gone to nothing." He was doing a lot of reading and talking to people to help him figure out about life after death. He longed for a sense of connection and said, "I still find it hard to think that we won't meet again. That's probably the hardest part."

Striving for Balance

Striving for balance refers to the ways in which FCGs tried to prevent themselves from becoming overwhelmed with the grief and the changes they experienced. In order to have balance to these challenging experiences, FCGs endeavoured to create some stability within themselves. The strategies that they used to create balance included maintaining routines, setting limits and boundaries, planning, and keeping a focus. These strategies seemed to help the FCGs manage their stress, "keep on a more even keel," and adjust to their lives without the person who had died.

Many of the FCGs said that *maintaining daily routines* provided some ongoing structure in contrast to the changes in their lives. For one man, doing daily household tasks helped with grief because he could find relief in doing things that needed to be done. Others maintained beneficial community connections such as church attendance and club involvement. For the FCGs who were employed, working was an important routine. One daughter said, “Regardless of what was going on in my emotional personal life, work was one place that I knew what I was doing and felt comfortable there.” Generally, routines seemed to give FCGs a sense of competence and self-confidence that helped them to keep a balance in their lives.

Being able to *set limits and boundaries* was a strategy that seemed to help FCGs to have some choice in when to grieve and when not to grieve. Several FCGs, for example, spoke about setting boundaries by saying no to offers of support when they did not want to talk about their loss. One FCG said no to support from her family doctor because she wanted to feel that she was okay and moving ahead:

I have to say that it was my choice, at that time [doctor’s appointment], to say, “No thank you. I don’t want to talk about this because I’m going to cry.” And I didn’t want to cry. I wanted to be able to think about things that were going to be making me able to handle everyday life easier.

Some FCGs set limits to give themselves a break from grieving; they engaged in activities that, as one daughter put it, “gave me a chance to remove myself from... the immediate in-your-face reality.” A woman, who had several family losses, said that she didn’t think it mattered what you did as long as you did not sit and dwell on grief. Setting limits meant taking things one day at a time, one step at a time, thinking about things when they were ready to do so, and safely expressing difficult emotions. One woman clearly described how she set limits and paced herself:

When I was ready to pull out all those little things that I knew that were going to be emotionally challenging for me, then I set limits for myself. In that, this is what you can handle today and this is what you're not going to be able to handle today. And I try to keep within those bounds, for myself. I think that it's okay for people to be emotional, to be angry, or whatever. But I don't think it's good for you to be like that all the time. I think you have to be able to set limits, so that you can think that you can handle the next stage.

In contrast, the FCGs who had young families found that they were so busy they did not have time to think and their emotions had to “take a back seat.” They expressed a wish for more time to pay attention to their grief and bereavement.

Making a plan provided structure in the FCGs' lives and helped them to be busy and active. One widower put things that he planned to do on his calendar:

I know it helped me a great deal, to have a calendar at the beginning of the week in which I had several things to do. And so that the day didn't begin with, what am I going to do today? There was always a few things there.

One daughter explained that she planned activities to fill her extra time with things she enjoyed. Several FCGs said that they were busier than they had been before caregiving and listed various social activities, church groups, and hobbies that were new to them. Making a plan seemed to help FCGs have pleasure in their days and a sense of control in their lives.

Some FCGs reported making a plan for special calendar events such as anniversaries, birthdays, and holidays was very helpful. One woman related that planning for the first anniversary of her husband's death made it easier to get through the day. Rather than staying in bed all day as she might have, she said, “I made it a really nice day and I did it all by myself.” Other FCGs planned family get-togethers or remembrances that helped them to have something positive to look forward to for these days.

Keeping a focus was connected with other aspects of striving for balance. It helped FCGs to maintain their routines and some emotional balance. One woman thought that it was very important to avoid too much focus on grief and to not allow grief to overwhelm her but to “try to continue with daily life.” Another woman focussed on logic to help herself maintain emotional equilibrium. When she started crying, she would think about her mother’s poor quality of life and suffering and how she would not want her mother to go on living in those circumstances. For one widow, keeping a focus was a challenge and a work in progress:

Sometimes you just have to bite the bullet and quit analyzing ... It’s been helpful. But I think I have a tendency to overdo it ... because you can worry things to death ... I try to do more grounding ... I’ve got this [mindfulness] meditation book and so I try and remember to do that ... So that’s what I try and come back to. Focus on the now. I can’t change the past. I can’t change anybody else. I can only change me. And it’s just trying to remember that, instead of spinning off into space.

It seemed that FCGs were striving to keep a balance between the grief they felt and a feeling of stability within themselves. Whatever balance FCGs were able to find benefited them through an increased sense of control and self-confidence in adjusting in bereavement.

Many FCGs reported that *exercise* was a beneficial activity that helped them in a number of ways in their bereavement. Several FCGs spoke about exercise and physical activity as important ways to take care of themselves. One FCG said that exercise was one area of her life in which she had some control. One woman was very clear that, if she got up and exercised in the morning, she felt better emotionally and her grief and depression were manageable for that day. Another FCG said that exercise was good for “clearing the mind and getting ...that negative energy out.” Exercise also provided

opportunities for FCGs to have respite from grief or to express their grief. For example, one woman found exercise beneficial as she got “a lot of stress relief from going for runs and focusing on the physical fitness of that because it gave me a chance to ... just totally block out what was going on in [my] life.” In contrast, another FCG reported that the combination of music and physical activity helped to express grief. “When I felt like I needed to deal with it [grief] or it was just bubbling over, I would just put on [some grieving and loss songs], go for a walk, and it would draw stuff out of me, help me to cry.” It seemed that, for FCGs, exercise and physical activity improved their well being and helped with adjusting in bereavement.

Appreciating the Good in Life

The FCGs seemed to notice positive aspects of their lives and the world so that they could appreciate and be grateful for them. Family caregivers expressed gratitude for a variety of things, including the small things in life. They searched for heartening moments to help themselves to bear the pain of the loss of connection with the person who died and the distress of the changes in their lives. Appreciating the good in life seemed to help FCGs to count their blessings and to begin to enjoy things. They reported that, in the midst of the challenges of their lives, it fostered a positive attitude that helped them to adjust.

Some FCGs were grateful for aspects of how their family member had died. A husband who cared for his wife at home said that the serenity and peacefulness of the way his wife died was a great gift. In recounting some positive aspects of the last weeks of caregiving, one daughter said:

One thing that I felt quite blessed with was having the way he [father] passed away. That’s been able to keep me peaceful and feel that we had a great

relationship ... I felt like if he had to have gone, he went out on top [of his] relationship with all of us ... I felt with him that we made the last moments count ... I don't feel like I could have done any more or any less ... We were up there. He knew that we cared ... We made it work so that we could be there for him and make him comfortable. So I feel like our relationship was good and strengthened. But I do, when I hear about [a] tragic car accident, I feel like it could always be worse. We were there for the last breath, for everything, so it was good.

In contrast, one FCG said that, despite some of positive things in her life that arose out of her caregiving and bereavement experiences, she was not grateful for these experiences.

All of the FCGs were grateful for help and support that they had received in their bereavement. Some of the FCGs were especially grateful for closeness in their family and better family relationships. One woman thanked God everyday for the improved relationship with her daughter. Some FCGs were thankful to feel more at peace in themselves or to begin to find their way in life. Also, FCGs were grateful for the progress that they made in their grief. One woman was grateful that things got easier little by little and she could appreciate the world:

First six months, it didn't feel like I was moving forward, but after awhile, yes, definitely I could feel it was getting easier. Life was kind of getting back to normal and I was starting to learn again. The sun shining was wonderful and little by little those things came along.

Many FCGs expressed appreciation for the beauty of the world. Despite the challenges in their lives, they reported that such appreciation could bring them comfort, happiness, and peace. One woman, when she was having a difficult time, would:

... [do] something that I enjoy doing. Throwing on a backpack and going for a walk up in the mountains or along a stream. Just somewhere where it was peaceful and quiet so that you can do some deep thinking on the good in life.

Several FCGs spoke about the peace and enjoyment they found working or relaxing in their gardens. One man regularly saw a butterfly in his garden. It became a symbol for

him that, despite his pain and loneliness, he still could treasure the times of happiness and joy in his life.

A few FCGs created opportunities for gratitude. For instance, one woman took her daughters on an overnight retreat. The family had experienced many losses over a ten year period, yet they stayed up much of the night talking about “all the wonderful good things” they had in their lives. For another woman, who also had several recent losses, gratitude was a way of life and she attributed much of her well being to this:

[I’m] trying to keep positive and grateful for all the things I do have, materially and spiritually and just in every way, physically ... It’s the way I try to live my life. I think if I didn’t have a positive attitude and the faith that I have I wouldn’t be doing nearly as well as I’m doing. It’s a huge benefit I think, mentally and physically. I think it’s good to be grateful.

Awareness of Personal Growth

Awareness of personal growth refers to the ways in which FCGs saw themselves differently as a result of their experiences in caregiving and bereavement. They saw themselves as better, stronger, more compassionate, and more aware of what was important in their lives. Some FCGs had experiences in bereavement that helped them to feel a sense of independence and accomplishment.

Family caregivers’ observations about personal growth often occurred in the context of questions, such as, “Has your outlook or way of thinking about life changed?” Sometimes FCGs spoke spontaneously about having grown through their caregiving and grieving experiences. One man expressed the importance of seeing himself in a positive way:

I am not a victim ... If I ever thought of myself as a victim, then I was in trouble ... It was very difficult those two years, but I was not going to let it destroy me. I wanted to grow from that.

One FCG said, “I know myself better,” and another said “I’m a stronger person,” adding that she knew how to be a caregiver and how to take care of herself afterwards. Some FCGs said they were more compassionate towards others and more willing to help. Several FCGs reported they had learned more about death. One woman said that her fear of death was less after caregiving for her father. Through caregiving for his life partner, a man had learned “how a human being can die with dignity.”

Some FCGs said that they had a new perspective on life after the person they cared for died that seemed to help them with adjusting. Some FCGs found that what really matters in life was very clear for them after their experiences of caregiving and death. These FCGs spoke about the importance of love and caring. One FCG realized how much “humans need each other” and another FCG was aware that love for your fellow man had to be put into daily practice. For several FCGs, a new perspective meant that they didn’t get so wrapped up in the small details of life or that they didn’t take these things so seriously. One daughter said that this perspective was present for her right after the death and then it was not always available but came and went.

Many FCGs said that they were more understanding of people who were dealing with death, dying, and bereavement. One widower recognized that, in the past, he had not been as supportive to grieving friends and relatives as he might have been. A daughter realized that knowing what to say or do to be helpful to a bereaved person is awkward:

It’s now that I’ve been on both sides, both having lost somebody and then dealing with people that have lost somebody ... I’ve just thought, “Oh, I don’t want to say anything stupid. I know how that made me feel. I don’t want to not do anything because that comes across as being not caring.” It’s such an awkward situation for everybody that it’s nice when you can open up to somebody who is there ... just to listen.

FCGS were more aware of the individuality of the bereavement experience and what could be helpful to a bereaved person, e.g., not assuming you know what is best for a person, listening, being present, answering questions, sharing experiences, and offering material demonstrations of caring. One daughter remarked that being able to help someone deal with the loneliness of grief meant that “there’s lots of odd, good things that [can] come from bad stuff.”

Several FCGs were aware of a strong feeling of accomplishment and independence when they took risks to try new things. For example, it was a struggle for one daughter to do any activity outside her home alone. She knew that she had to do something about this disabling aspect of her bereavement, so she signed up to learn to row, which she had always wanted to do. This approach to her difficulty not only gave her confidence that she could adjust in bereavement but also that she could expand her horizons:

Initially, it was, “What am I doing? I don't have any social skills. I don't know what to do.” But I found that [the rowing class] gave me something to look forward to at a time when I was struggling to find something to look forward to. And I think that really, initially, started helping me realize that I'm okay, that I can do this [adjust to losses], not on my own, but I can do this. I can survive from this [death of parents]. Yeah, so I did that. And after I did it, as small and simple as it sounds to me, I was so proud of myself that I had followed through with something that I had been struggling to do for so long. I think that was the snowball of other things. I felt more like, “Oh, I could try this on my own ... I'll try it now.” So I started to get more confidence doing things on my own.

A widow decided that she wanted to visit relatives and friends who had known her husband and she drove herself across the country. She said that it was an excellent decision on her part as people accepted her and gave her great support. More than that, it gave her a strong sense of her own power:

I got in the car and I sort of felt free ... I felt empowered. That's how I felt. I felt empowered. I am going to drive myself all the way over there and I'm going to visit all my friends and my relatives and his friends and relatives and I just went for it. Turned the old stereo on and just boot it.

In talking about personal growth, several FCGs were clear that it came at a steep price. One woman said, "I would rather have learned these things a different way." However, awareness of personal growth seemed to allow FCGs to consider the benefit to them of having been a caregiver and a bereaved person. Being aware of their own positive changes and personal growth seemed to be one way for FCGs to gauge their adjustment in bereavement.

The FCGs used many different personal resources, strategies, and tools to help themselves deal with their loss and the changes in their lives. They actively engaged in their own adjustment process by utilizing their resources to comfort themselves and promote their personal well being. The ways that they found to manage and to adjust in bereavement helped them to feel a connection with the person who died, to structure their lives in new ways, to appreciate and enjoy many aspects of their lives, and to recognize ways in which they had grown. This mobilization of the FCGs' own resources seemed to be a central aspect of what helped them to adjust in bereavement.

Summary of Findings

From the analysis of the data, a description of the bereavement experiences of FCGs emerged. Family caregivers experienced the impact of the loss, the need for a safe community, and active engagement in adjusting in bereavement. These experiences were not encountered in a linear fashion. They were the felt consequences of the death and the FCGs' responses to it that were occurring during their bereavement.

The impact of the loss was experienced by FCGs in several ways. The death of the person for whom FCGs were caring brought dramatic changes to FCGs' lives. Family caregivers experienced painful responses to the loss of connection with the person who died and missed the person deeply. The FCGs also experienced unsettling changes in themselves, in their identity, as so much changed for them following the death. These powerful experiences occurred simultaneously for the FCGs and could be overwhelming.

The need for a safe community was expressed by FCGs as a need to be accepted and supported by those around them. The experiences that FCGs reported included support efforts that were unhelpful and could be distressing. The support that FCGs described as helpful included reassurance about themselves and their grief, comfort, understanding, and caring. The relationships within which FCGs found these qualities provided them with a safe community in which to grieve.

Bereaved FCGs clearly described various ways in which they were able to help themselves in adjusting to bereavement. These strategies for actively engaging in their own adjustment began immediately following the death and continued throughout the period for which they had been bereaved.

The participants in this study reported that, despite what people told them, they did not feel strong. They felt overwhelmed, lonely, and anxious. Yet, they spoke about having and creating strong personal ties with a community of people who cared about them and shared in their bereavement. Each of these FCGs found personal and social resources that helped them. In the context of the immensity of change and the depth of grief that accompany the loss of the loved and cared-for person, it was humbling to hear

the FCGs in this study acknowledge that they were devastated *and* that they were simultaneously engaging in adjustment in their bereavement.

CHAPTER 5

Discussion

This study provides rich descriptions of the experiences of bereaved FCGs with uncomplicated grief and identifies what these FCGs found challenging and helpful related to their adjustment to the loss of the cared-for person. Once again, it is important to understand that uncomplicated grief applies to a wide range of individuals with varying bereavement experiences. Loss is painful and grief is difficult. The FCGs in my study described intense and sorrowful experiences as well as awareness of growth and adjustment. The findings from my study are illustrative of the *challenges* faced by the FCGs. The impact of the loss was major and presented challenges as the FCGs were experiencing a magnitude of changes in their lives, grief at the loss of connection with the person who died, and vulnerability with the changes in themselves. Needing a safe community in which to grieve included challenges for the FCGs such as getting the kind of support they felt that they needed and encountering unhelpful social expectations. The findings are also illustrative of *what was helpful* to the FCGs. Finding a safe community in which to grieve was helpful to the FCGs when it included accepting grief as normal and justified and getting validation as a bereaved person. The quality relationships and shared experiences were of major help to the FCGs in terms of support from others. In my study, the FCGs were remarkable for their active engagement in their own adjustment. They used personal strengths and resources to help themselves manage the challenges that arose following the death of the person for whom they had been caring.

In this chapter, findings from my study are discussed in the context of the models of grief and adjustment that were presented earlier. Then the discussion relates the findings to pertinent literature. Certain caveats relevant to the scope of this study are

presented and the limitations summarized. A discussion of findings related to implications for bereavement care practice and policy follows. Future directions for research are suggested. A summary of the significance of my study closes the chapter.

Models of Bereavement and Adjustment

In my study, the findings include a range of bereavement experiences of the FCGs with uncomplicated grief. This range is similar to the *adaptation to bereavement model* (Schuchter & Zisook, 1993). Schuchter and Zisook (1993) described a broad range of positive and negative bereavement experiences across six dimensions in which adaptation to bereavement occurred (emotional and cognitive experiences; coping with loss; continuing relationship with the person who died; functioning; social and intimate relationships; identity). What is different about my study is that the findings distinguish between the problems that the FCGs described (challenges) and the ways in which they managed these problems (what was helpful). In particular, the findings give clear information about the behaviours that helped the FCGs. This information has potential to help other bereaved FCGs in managing their challenges and in adjusting in bereavement.

Striving for balance was an important way for the FCGs in my study to manage various challenges bit by bit and to have respite from those demands. These findings fit with the process of oscillation in the *dual process model of coping in bereavement* (Stroebe & Schut, 1999). The findings in my study suggest that the challenges for FCGs in bereavement were similar to the loss-oriented and restoration-oriented stressors included in the dual process model (Stroebe & Schut, 1999). However, the findings in my study suggest that the factors described by the FCGs were not necessarily loss or restoration specific, but could be helpful in both areas. Thus what was helpful is

separated from stressors (challenges). Stroebe and Schut (1999) suggested that the cognitive strategies used in coping with bereavement were denial, confrontation, and avoidance. The findings from my study suggest that further cognitive strategies used by the FCGs with uncomplicated grief were remembering, appreciation, and awareness of personal growth.

In my study, FCGs often spoke about the illness and death of the cared-for person and about their personal, social, and occupational lives before caregiving. The influences of their former lives were a background against which bereavement was experienced. These contexts of the FCGs' lives in which caregiving and loss occurred correspond to the personal, situational, and interpersonal and environmental contexts described by Stanton and her colleagues (2001) in the *model of adjustment in chronic illness*. It may be that these contexts have more effect on adjustment in the first year of bereavement. For the FCGs in my study, the contexts of their lives had changed over the 18 months to 4 years since the death of the cared-for person. It seems that adjustment in bereavement was an iterative process for the FCGs in which changes in the contexts of their lives had to be managed and managing them led to further changes in the contexts. Findings suggest that managing the changes well helped the FCGs to have more confidence in managing in the future. No research was found on this sort of feedback over time and this is an area for further research.

FCGs' Experiences of the Impact of Loss

Findings suggest that these FCGs with uncomplicated grief had intense experiences following the loss of the cared-for person. The magnitude of change was challenging for the FCGs. They were overwhelmed and alone and felt intense longing,

sadness, and neediness in the face of the changes in their lives. The literature suggests that caring for a family member through their last days and being bereaved are both major life events that bring life-altering changes (Addington-Hall & Karlsen, 2000; Bernard & Guarnaccia, 2003). My study findings support this view as the FCGs described fundamental changes across many aspects of their lives.

In my study, findings suggest that the loss of connection with the person who died was central to the FCGs' experiences in bereavement. Missing this cherished connection and the person touched every other aspect of the FCGs' bereavement experiences. In the literature, two aspects of grief related to missing are longing and yearning. Longing is considered a normal grief reaction (Stroebe et al., 2007) whereas yearning for the deceased is a criteria for complicated grief (Prigerson et al., 1995). In my study, the loss of and missing the connection with the person who died was pervasive and challenging. It may be that the nature of missing is distinct from either longing or yearning. The loss of connection and missing the person who died may be overlooked as major challenges for FCGs with uncomplicated grief. The FCGs suggested that it was imperative for health care professionals and others to understand the impact of loss in order to be helpful to them or to bereaved individuals more generally.

Findings suggest that not only were the FCGs overwhelmed by changes and deeply missing their connection with the person who died but also they felt vulnerable because of personal changes in their identity, roles, and responsibilities. The FCGs described the shifts in their identity as very difficult, e.g., not knowing themselves, losing the meaning and purpose of their lives. These shifts in their personal identity and purpose happened at a time when the FCGs also were struggling with changes in their lives and

missing the person who died. The resulting vulnerability may in part explain the intensity of FCGs' experiences and the length of time that these experiences continued. New roles, identities, and relationships are included within restoration-oriented stressors in the dual process model of coping in bereavement (Stroebe & Schut, 1999). However, in my study, the FCGs' experiences of personal changes had such major impact on their adjustment that these experiences presented a unique area of challenge. As Moules and her colleagues (2007) said, "...after having lost loved ones, the bereaved find themselves lost also" (p. 129).

Needing A Safe Community In Which To Grieve

Needing a safe community does not seem to appear in the literature in the same way that FCGs in my study described it. The need for a safe community in which to grieve may have become apparent in my study due to the broad scope of the interview questions that extended beyond individual social support efforts. From the FCGs' descriptions, a clear portrait emerged of what was challenging and helpful to them in bereavement within the social context. Lehman and his colleagues' (1986) qualitative study provided initial research on helpful and unhelpful social support efforts following a sudden death. My findings are similar to those of Lehman and colleagues (1986), however, the FCGs in my study emphasized the importance to them of safety and comfort within relationships and groups. The literature on social support in bereavement focuses on certain aspects of support such as increases and decreases in support (Chentsova-Dutton & Zisook, 2005; Unger & Florian, 2004; van Baarsen, 2002) and social loneliness (Stroebe et al., 1996; van Baarsen, 2002). In contrast, in my study, the FCGs' described complex networks of social connections within which support occurred.

An aspect of social support evident in my study, but not found in the literature, is the finding that the FCGs wanted to be accepted as changed by their loss and in need of succour from the people around them. They wanted their suffering to be understood and acknowledged. However, they experienced misguided offers of support from family, friends, acquaintances, and helping professionals. They were distressed by these experiences and the consequences that they described included increased isolation, avoidance of supporters, and lack of honesty about their well-being. Lehman and his colleagues (1986) pointed out that the disparity between the positive intentions of support providers and the negative perceptions of recipients was unhelpful to suddenly bereaved individuals. These findings and the findings from my study suggest that instances of misguided support deserve attention as challenges to adjustment in bereavement.

Often, the challenges of getting support that FCGs encountered were based on the supporter's mistaken or prescriptive information about grief, bereavement, and supporting a bereaved person. Findings suggest that offers of support were not tailored to the individual needs of the specific FCG. Other studies have found that social support in bereavement can be fraught with challenges due to the complex nature of providing support (Lehman et al., 1986; Ungar & Florian, 2004). The findings from my study indicate that one of the great challenges in providing helpful support to these bereaved FCGs was finding a balance between having knowledge of common bereavement experiences and understanding the needs of a particular individual.

Adjustment in bereavement happens in the social context of family, friends, and community. Findings from my study suggest that it is within the social context that a safe community in which to grieve is found. Social support may be positive or negative

(Lehman et al., 1986; Wills & Fegan, 2001) and the FCGs in my study described both. Their descriptions of positive social support indicated the value to them of a safe community and the important components of this community (validation and justification, quality of relationships, sharing a common experience). It has been suggested that strengthening the support network of a bereaved individual with uncomplicated grief will assist that individual's adjustment (Hansson & Stroebe, 2003). Findings from my study support that suggestion as one way to assist FCGs with their adjustment.

In my study, findings suggest that in a safe community of support the FCGs' grief was accepted and they were reassured of the normality of their responses to loss. These FCGs indicated that understanding their grief as normal (through information, validation, and justification) was helpful to their adjustment as it decreased their anxiety about challenges in their changed lives, their grieving, personal identity, and their equilibrium. Negative interpretations of grief reactions have been associated with higher levels of distress, avoidance behaviours, and severity of grief symptoms (Boelen et al, 2003). The FCGs in my study reported that the provision of information about normal grief alleviated their distress and was beneficial to their adjustment in bereavement.

The bereaved FCGs provided a description of the qualities of a supportive relationship that were important to them. These qualities include warmth, acceptance, understanding, comfort, and caring. The FCGs felt safe with supporters who were consistent, available, and trustworthy. It appears that the presence of family and friends is helpful to bereaved individuals (Bass, Bowman, & Noelker, 1991; Chentsova-Dutton & Zisook, 2005). However, there is little indication of what it is about this presence that

promotes well-being and adjustment in bereavement for the bereaved individual. The qualities of relationships and characteristics of supporters described by the FCGs in my study may be indicators of how the presence of family and friends helps bereaved individuals.

The FCGs described many examples of support within their connections with other bereaved individuals. They reported that they learned about strategies, found role models, had their grief accepted and normalized, and shared social activities. These findings indicate that the FCGs felt understood and safe in their connections with other bereaved individuals. Suitor and Pillemer (2000) found that bereaved FCGs of elderly relatives preferred support from similar others. The FCGs of elderly relatives reported that the benefits of support from other bereaved people were twofold, having their needs understood and being able to talk openly about their thoughts and feelings (Suitor & Pillemer, 2000). In my study, the FCGs described learning helpful behaviours and ways of thinking from sharing with other bereaved individuals. These findings are in keeping with Benight and colleagues' (2001) findings that the modelling of effective coping by other widows helped to promote self-efficacy for cancer widows. In my study, the FCGs' accounts of support from other bereaved individuals may indicate what is helpful in support communities of similar others and why this type of support is one of the preferred types. The FCGs' descriptions point to the potential richness of social support among bereaved individuals.

In my study, the FCGs valued their connections with other bereaved individuals. They appreciated the comfort and practical information that they received from these connections. There is little evidence within the intervention literature of the value of

connections among bereaved individuals (Schut et al., 2001). Often the goal of bereavement care intervention, and the outcome measure, is the alleviation of grief symptoms (Neimeyer, 2000). In contrast, the FCGs in my study reported that they valued bereavement support interventions, such as groups, as they were able to share their grief and cry openly. Rather than alleviation of grief, the important outcomes for the FCGs were learning how to manage grief and to adjust to the changes brought about by loss. Supportive groups allowed the FCGs to feel more comfortable in themselves without necessarily changing their experiences of grief. Moules and her colleagues (2007) suggested the value of bereavement groups included the commonality of experience that provides a ground for each person's grief journey. The commonality of experience with other bereaved individuals and hearing their stories helped FCGs in my study to understand their own grief as normal and doable. However, not all FCGs who attended a group found the particular group helpful, demonstrating that there is no "one size fits all" in bereavement care interventions. For many FCGs in my study, a safe environment in which bereaved FCGs could meet to share and discuss their stories, problems, and successes was experienced as helpful in their adjustment.

Active Engagement in Adjusting

My study involving FCGs with uncomplicated grief provides a portrait of the relationships, resources, and strategies that were helpful in the FCGs' adjustment in bereavement. In the recent related literature, there has been growing interest in positive aspects of bereavement (Davis et al., 1998; Moskowitz et al., 2003; Ong et al., 2004). Findings from my study suggest that active engagement in adjustment includes a number

of positive behaviours and strategies used by the FCGs in facing the challenges of loss and bereavement.

The components of active engagement in adjustment may be related to resilience. The construct of resilience was described by Luthar and her colleagues (Luthar, Cicchetti, & Becker, 2000) as a dynamic developmental process of positive adaptation in the presence of adversity¹. Bonanno (2004) suggested that the adversity could be a “potentially highly disruptive event such as the death of a close relation” (p. 20) and that positive adaptation was the ability “to maintain relatively stable, healthy levels of psychological and physical functioning ... as well as the capacity for generative experiences and positive emotions” (pp. 20–21). Bonanno and colleagues (Bonanno, 2004; Bonanno, Wortman, Lehman, Tweed, Haring, Sonnega, Carr, & Nesse, 2002) found that resilience had a positive influence on bereavement outcomes such as levels of depression and grief symptoms. In my study, the FCGs described in detail what they did that helped them to be resilient in facing the adversity of a major loss which suggests that the FCGs consciously chose and worked at behaviours such as maintaining daily routines and remembering positive times with the person who died. They reported that they learned some strategies such as setting limits and boundaries from helping professionals and from sharing ideas and options with other bereaved individuals. These findings may add to knowledge of the substance and practice of resilience and of factors that promote adjustment in bereavement.

In my study, the FCGs described how remembering the person who died changed over time as their adjustment in bereavement progressed. Although initially many memories were painful, when they were able to, the FCGs set aside the painful memories

¹Luthar and her colleagues (2000) differentiated resilience from ego-resiliency. Resilience is a dynamic process whereas ego-resiliency is a personality trait and resilience presupposes substantial adversity whereas ego-resilience does not.

and chose to reminisce about and share good memories. These strategies helped to lessen the pain of remembering and to increase comfort and pleasure in remembering the past with appreciation and satisfaction. Somewhat similar are the findings of Moskowitz and colleagues (2003) that responsible self-care, sharing, and pleasure were positive states of mind that protected caregiving partners of men with AIDS against elevation of depressive mood in bereavement. However, those findings were not related to memories of the person who died. No studies were found that looked at the effects of memories on bereavement adjustment although a number of studies were found that focussed on the effects of bereavement on memory functions such as memory for past events and retrieval (Field, Thompson, & Gallagher-Thompson, 2006; Golden, Dalgleish, & Mackintosh, 2007). In my study, remembering the person who died was identified as a factor in adjustment to bereavement that shifted from being challenging to being helpful for the FCGs. This is an area for further study.

After the loss of their previous connection with the cared-for person, the FCGs began to develop a different connection in bereavement that continued to be important to them. The FCGs spoke of the positive value that a sense of presence, honouring the person who died, and beliefs about continuing existence and reunion had for them in adjusting in bereavement. These findings are in keeping with current research on continuing bonds (Klass, 2006; Neimeyer, 2006). Klass (2006) described continuing bonds as normal bereavement experiences of interactions with the dead that reconstruct the social identity of the person who died in the context of family and community. All of the FCGs in my study spoke in a positive way about their connection with the person who died. However, Klass (2006) made the point that these bonds are not necessarily helpful

and must be considered on an individual basis. Still, it may be that understanding the potential importance of a different connection for some FCGs could help professionals to support those FCGs in bringing the person who died forward in their lives in a new way (Cairns et al., 2003).

Striving for balance was one behaviour that helped FCGs with adjustment in bereavement. Through maintaining routines, setting limits, making plans, and keeping focus, the FCGs avoided being overwhelmed by loss and change. They described how they strove to balance attending to their grief, having respite from it, and attending to the other aspects of their lives. They managed this fluctuating balance for themselves through conscious attention to their capabilities in the moment and to their own well-being. Stroebe and Schut (1999) and Lindstrom (2001) suggested that a balance of the competing expression and control processes in bereavement was best suited to positive adjustment in bereavement. Stroebe and Schut (1999) also suggested that the regulatory mechanism of oscillation in coping with bereavement stressors is necessary for optimal adjustment. The strategies used by FCGs in my study in striving for balance may begin to explain how expression and control processes and regulatory mechanisms manifest in the lives of bereaved FCGs with uncomplicated grief.

A focus on appreciating the good in life helped the FCGs to generate and maintain a positive outlook. The findings suggest that positive emotions, such as gratitude, appreciation, and satisfaction, were helpful to the FCGs' adjustment in bereavement. The presence of two positive emotions, humour and love, were linked with reports of lower levels of stress and depression for older widows (Ong et al., 2004). The broader range of emotions reported by the FCGs in my study may be attributed to the frankness with

which they spoke and to the more open-ended nature of qualitative research using interpretive description. For these bereaved FCGs, reviewing their positive memories of times with the person who died and making opportunities for positive emotions were beneficial in their adjustment.

Awareness of personal growth helped the FCGs to see themselves as better, stronger, and more compassionate because of their caregiving and bereavement experiences. Davis and colleagues (1998) reported that finding benefit in a challenging situation such as the death of a significant person had a positive influence on depressive symptoms, post-traumatic stress symptoms, and positive affect. In Davis' study, finding benefit was associated with decreasing distress over time beyond the first year (Davis et al., 1998). In my study, the FCGs were all beyond the first year of bereavement and reported that awareness of personal growth was a helpful aspect of their adjustment. The FCGs' descriptions of personal growth also illustrated positive experiences, such as reaching out to help others, experiencing independence, and recognizing accomplishment. Benight and his colleagues (2001) found that self-efficacy positively influenced bereavement outcomes, such as psychological and spiritual well-being. They also found that mastery experiences helped to promote self-efficacy (Benight et al., 2001).

In my study, the FCGs gave specific examples of learning new things or new ways to do things that helped to build their confidence in their own abilities. Also, the FCGs' awareness of personal growth included assessments of how they had changed and how they were managing. In the model of adjustment to chronic illness, Stanton and her colleagues (2001) included appraisals of one's own adjustment as a coping process that

fostered adjustment. The FCGs in my study monitored their own progress and checked their experiences against those of other bereaved individuals. They said that they had a new perspective on life and that they were clearer about their personal values and priorities. Loss and change may have been the catalysts for these aspects of personal growth as the FCGs needed to adjust to the distressing changes in their lives and in themselves. Because of their experiences of caregiving and bereavement, the FCGs saw themselves as resources for other bereaved individuals. Having experienced bereavement sensitized the FCGs to the challenges of offering support and the importance of doing so. No literature was found related to a new perspective or to bereaved individuals seeing themselves as resources for others. However, both were important factors in awareness of personal growth for the FCGs.

The FCGs in my study may have been aware of their personal growth in part due to the influences of the time that had passed since the death of the cared-for person. Their reports of awareness of personal growth arose in the context of in-depth interviews about personal experiences of how things had changed following the death of a significant person. These FCGs were reflective, articulate individuals who were managing relatively well (uncomplicated grief) and aware of many aspects of their adjustment in bereavement. Other FCGs may not reflect or even experience changes in the same way. However, it may be that bereaved FCGs with uncomplicated grief who have awareness of personal growth could provide good models of achievable adjustment for similar others. Further research is needed to investigate the value of role models in adjustment in bereavement.

Caveats and Limitations of the Study

The findings of my study apply to the group of FCGs who participated and may or may not apply to other groups. In keeping with my purposive sampling criteria, the FCGs with uncomplicated grief in my study were thoughtful and articulate. They had reflected on their experiences throughout the time that they were bereaved. These characteristics may not be shared by other bereaved FCGs and their views of bereavement may differ. The experiences of other FCGs may be quite different from those of the FCGs in my study. However, the FCGs in my study gave rich descriptions of their experiences in bereavement and much may be learned from them.

The FCGs in my study all lived in the south Vancouver Island Health Authority region. In this region, hospice palliative care programs are available in palliative care units, some care facilities, and in the community. These programs cared for the ill person when necessary and enabled some of the FCGs to care for the ill person at home. A range of bereavement care options were available to the FCGs through the Victoria Hospice Society or other community organizations and hospices that offered particular bereavement care services. The availability of palliative care and bereavement care resources may have shaped some of the FCGs' experiences in bereavement. Experiences of FCGs from regions with fewer services available may have different experiences than the FCGs in my study.

This research was undertaken to fulfill the requirements of my Master's program and as such is the work of a novice researcher. The small sample size may limit the extent of the implications that can be drawn from the findings. The study participants were all Canadians of European decent, from one area of Canada, and the findings are descriptive

of this group. Family caregivers with other backgrounds and from other areas may have different experiences than the participants in my study. Despite these limitations, the data are rich and valuable in describing the bereavement experiences of these FCGs with uncomplicated grief.

Implications for Practice and Policy

There are findings from my study that appear to have implications for health care and other professional interventions with bereaved FCGs with uncomplicated grief. For example, the FCGs in my study described the diverse ways in which they helped themselves to manage their challenges and adjust in bereavement. It may be important for professionals offering bereavement care support to consider that helpful behaviours and strategies can be learned. Educational interventions for bereaved FCGs could assist them to consider new ways of managing and allow them to practice strategies in a supportive community.

The benefits that the FCGs in my study attributed to connections with other bereaved individuals suggest that creating opportunities for bereaved individuals to connect might be a potentially helpful intervention. The FCGs in my study saw themselves as resources for other bereaved individuals and it may be that occasions to give as well as receive promote self-efficacy. Opportunities for learning and sharing, within the context of a safe community, seemed to promote adjustment in bereavement. Also, the FCGs in my study found that both sharing with other bereaved individuals and information about grief helped to normalize their experiences and reduce their distress. Information materials are a cost-effective intervention that can help bereaved FCGs to

understand their bereavement challenges and to support their efforts towards helping themselves.

Education and information may also benefit supporters of bereaved FCGs in learning how their presence can be helpful to a bereaved individual. The kinds of support efforts and qualities of relationships described by the FCGs in my study provide some insight into support behaviours to avoid and support behaviours that promote safety and comfort. Such education is one way for professionals to strengthen the support networks of individuals with uncomplicated grief as suggested by Hansson and Stroebe (2003).

The findings from my study also suggest a need for education about grief and bereavement generally. Such education about the impact of loss and its characteristics and the challenges of needing a safe community could provide a foundation for appreciating the deep experiences of FCGs with uncomplicated grief. Education about the more positive experiences of bereaved FCGs with uncomplicated grief could provide a foundation for understanding what is helpful and promotes adjustment for this group. It also could include information about individual differences as well as common experiences and support strategies that balance these perspectives. General education about bereavement could be tailored to provide in depth information for professionals or to offer a helpful overview for the general public.

The findings of my study have implications in relation to help-seeking also. Although the Center for the Advancement of Health has suggested that bereaved individuals with uncomplicated grief are unlikely to benefit from intervention, others have suggested that there will be individuals with uncomplicated grief with bereavement care needs (Kristjanson et al., 2005; Walsh-Burke, 2000). The FCGs in my study sought

assistance with their adjustment in bereavement from formal support resources including doctors, ministers or pastors, counsellors, classes on grief, bereavement support groups, and walking groups. The FCGs sometimes used several types of these formal supports. Although in the minority, not all the assistance sought from or offered by professionals was experienced as helpful by the FCGs. FCGs thought that certain professionals had no idea how to talk to them or how to be helpful. It is possible that these professionals had insufficient training in providing bereavement care and/or no personal experience to offset their lack of training. In my study, the FCGs were clear about the value of good professional support. Training in how to interact with and support bereaved FCGs could benefit health care professionals and other helping professionals in their practice.

The FCGs in my study who were connected with a hospice program got information about available services that may have influenced their decision to seek help. However, other FCGs who were not connected to a hospice program sought out bereavement groups and classes in their community. Findings suggest that, despite having good existing supports, the FCGs still had needs for validation, justification, understanding, and comfort. The challenges of the global nature of the impact of loss and personal identity may be two reasons why FCGs with uncomplicated grief ask for help. Aranda and Milne (2000) suggested that individuals with uncomplicated grief manage with their own natural supports. However, findings from my study indicate otherwise as these FCGs with uncomplicated grief asked for help from formal supports. One possible explanation is that professional and group support are part of FCGs' natural supports. In any case, when bereaved individuals with uncomplicated grief seek help, professionals need to respond in helpful ways. Health care and other professionals need to avoid

assumptions about who will and will not benefit from assistance with their bereavement and to assess carefully the individual needs and resources of bereaved FCGs.

Normalizing help-seeking behaviour for bereaved individuals with uncomplicated grief may be beneficial to bereavement care practice in several ways. First, bereavement care providers could be prepared to respond in helpful ways. Second, if help-seeking was seen as natural, any stigma that might be attached to help-seeking may be removed. Normalizing help-seeking in bereaved individuals with uncomplicated grief may make it easier for those with complicated grief to ask for help. Third, help-seeking may allow health care and other professionals to provide bereavement care aimed at promoting adjustment and at averting negative patterns that might lead to complications.

In order to implement interventions and to promote help-seeking behaviours among bereaved FCGs, policies that support changes in education and programme planning would be needed. Many bereavement care programs are attached to hospice palliative care programs. Policies to develop programs and education are currently the responsibility of each organization. The Canadian Hospice Palliative Care Association is working on standards and guidelines for the provision of bereavement care to assist organizations with policy and planning. Findings such as those from my study provide initial information about the bereavement experiences of FCGs in hospice palliative care that may be helpful in developing standards and policies and planning intervention programs for this population. The findings from my study also suggest that information provision and supportive groups were beneficial to the FCGs' adjustment in bereavement. Such cost-effective interventions may be considered useful in program planning.

Directions for Further Research

As noted earlier, there has been little research focussed on FCGs in hospice palliative care and on individuals with uncomplicated grief. This study provides an initial exploration in these areas and points to the need for further research in a number of directions. In this section, I suggest research related to bereaved FCGs in terms of their experiences and behaviours. Research related to adjustment in bereavement related to factors that promote adjustment and theoretical models is suggested also.

Further qualitative research is needed that extends to other groups of bereaved individuals with uncomplicated grief to describe their experiences of what is challenging and what is helpful in adjustment in bereavement. Such research would contribute to an understanding of how individuals manage relatively well and adjust in bereavement. Quantitative research might then examine the prevalence and generalizability of bereavement experiences.

Also, further research that focuses more specifically on particular FCGs, such as daughters, daughters-in-law, sons, and siblings, is needed. Each of these groups is underrepresented in the bereavement literature as most work pertains to bereaved parents of young children and bereaved spouses. Younger FCGs also are underrepresented in the literature. Knowledge of the bereavement experiences of these groups could point out similarities and differences among them thus informing bereavement care practice.

Although there is information about the frequency of FCGs with uncomplicated grief requesting help from health care and other professionals, very little is known about the help-seeking behaviours of this group. No studies were found that specifically addressed the help-seeking behaviours of bereaved individuals with uncomplicated grief.

Help-seeking, therefore, is an area for further investigation. Research might consider the issues that lead FCGs to seek help and the outcomes of help that they anticipate in order to create knowledge to guide appropriate bereavement care responses.

Several areas of social support described by the FCGs in my study would benefit from further study. Misguided offers of support presented challenges to adjustment in bereavement for the FCGs. Further knowledge of the origins of these offers and their effect on bereaved FCGs would inform education for both bereaved FCGs and their supporters. Further research into the support behaviours of family and friends could suggest what is helpful to bereaved individuals. The importance of connections with other bereaved FCGs expressed by the FCGs in my study suggests that there may be value in these relationships that has not been recognized in the academic literature. Further research might address this gap through different approaches to study design, intervention goals, and bereavement outcomes. Bereavement care practice often includes supportive groups (Demmer, 2003) but evidence to suggest helpful characteristics of such groups is lacking.

In my study, descriptions of what was helpful to the FCGs indicate factors that promote adjustment in bereavement. Further qualitative research is needed to round out a picture of these factors that influence adjustment. Quantitative research is needed to indicate the prevalence and generalizability of the strategies and behaviours related to these factors. Detailed examples of strategies and behaviours related to factors and influences would add to knowledge of positive experiences and practices of bereaved individuals with uncomplicated grief. For example, although initially challenging, remembering the person who died became a helpful strategy for the FCGs in my study.

As no studies were found on memories of the person who died, examination of the role of memories in bereavement and the transition of that role is yet another area for further study.

The theoretical models of bereavement presented earlier (Schuchter & Zisook, 1993; Stroebe & Schut, 1999) are frameworks for understanding the process of adjustment in bereavement. Findings from my study point to areas for further research in relation to these models. For example, as described by the FCGs in my study, striving for balance included examples of managing expression and control and of regulating time, energy, and focus for various aspects of their lives. Research focussed on describing expression and control processes and regulatory mechanisms may add to our understanding of how these aspects of the models function in the lives of bereaved individuals. Also, the function of feedback over time suggested by the FCGs' experiences of challenges and managing were not found in the theoretical models or in other studies. Both these areas of research would contribute to greater knowledge of adjustment processes in bereavement.

Summary of the Significance of the Study

The majority of bereaved FCGs in the context of hospice palliative care have uncomplicated grief. As many of these FCGs ask for help from health care and other professionals, understanding their experiences in bereavement is essential to provide a foundation for identifying their needs and suitable responses. This study provides an initial examination of the bereavement experiences of FCGs with uncomplicated grief in the context of hospice palliative care.

The FCGs in my study described their experiences, the challenges they faced, and what was helpful to them in adjusting in bereavement. This foundational information brings forward salient features of the FCGs experiences. The challenges and what is helpful to bereaved FCGs with uncomplicated grief are introduced as unique concepts. Findings from my study highlighted the potential importance of understanding the impact of loss for these FCGs and can help health care and other professionals to respond appropriately to FCGs with uncomplicated grief. The absence of this understanding means that the needs of these FCGs may be underestimated or even ignored. For FCGs with uncomplicated grief, personal changes may have a greater role in adjustment in bereavement than is generally attributed to them. Health care and other professionals may be helpful to bereaved FCGs by assessing the impact of personal changes on their adjustment in bereavement. The findings that the FCGs needed a safe community in which to grieve and reported benefits from interactions with other bereaved individuals challenges current thinking that interventions are not helpful and may be harmful to individuals with uncomplicated grief. The implications arising from these findings suggest that health care and other professionals should be ready to offer a variety of supports to FCGs with uncomplicated grief. The knowledge gained from the FCGs' insights into their active engagement in adjustment in bereavement has the potential to help other FCGs to manage the challenges that accompany loss.

By describing the bereavement experiences of FCGs with uncomplicated grief, my study informs bereavement care practice for and future research with this population. This study may benefit health care and other professionals by providing knowledge of the challenges that accompany loss. Descriptions of what these FCGs found helpful in

managing the challenges and adjusting in bereavement may help professionals in offering helpful interventions and education aimed at similar bereaved individuals. Findings from my study are congruent with findings from other studies but also open up new understandings and areas for research with FCGs with uncomplicated grief in hospice palliative care.

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Appendix A – Definitions

Definition A1 – Criteria for Complicated Grief

Definition A2 – Family Caregiver

Definition A1 – Criteria for Complicated Grief

Criteria for complicated grief include that sufferers experience: (1) bereavement by death; (2) an intrusive and a distressing set of core symptoms which include yearning, longing for, and searching, that persist beyond 6 months; (3) four or more marked and persistent symptoms of traumatization such as, avoiding reminders of the person who died, purposelessness, feelings of futility, difficulty imagining life without the person who died, numbness, detachment, feeling stunned/dazed/shocked, feeling that life is empty or meaningless, sense that a part of oneself has died, disbelief, excessive anger related to the death, and symptoms similar to those suffered by the person who died (Prigerson & Jacobs, 2001).

Definition A2 – Family Caregiver

FAMILY CAREGIVER: anyone (related or not) who provides care for someone who is seriously ill and is not paid to do so.

CARE: anything you do for the person because he or she has a serious illness. Some examples are:

- Household chores you took over
- Household chores that now take more time (for example, extra laundry or preparing special foods)
- Outside chores (yard work, snow removal, running errands, shopping) that you took over or now take more time
- Banking and paperwork that are new, you took over, or now take more time
- Direct care for the care recipient (bathing, feeding, skin care, giving medications, wound care, toileting, transferring between bed and chair)

- Additional time you spend with the care recipient, including keeping him or her company and being present for safety reasons
- Arranging appointments, arranging for help from paid or unpaid others
- Attending health care appointments
- Transportation
- Time spent in the hospital

Appendix B – Letters of Invitation

What Helps Bereaved Family Caregivers Adjust to Their Loss
An Interpretive Descriptive Study

Researcher: Moira Cairns, BA, RSW
 Junior Graduate Trainee
 Michael Smith Foundation for Health Research
 University of Victoria

Faculty Advisor: Kelli I. Stajduhar, RN, PhD
 New Investigator, Canadian Institutes for Health Research
 Scholar, Michael Smith Foundation for Health Research
 Assistant Professor
 School of Nursing and Centre on Aging
 University of Victoria

Letter of Invitation to Participate in a Research Project

Hello,

I am a student in the Interdisciplinary Master of Arts program at the University of Victoria. I am also a registered social worker with a background in hospice and bereavement counselling. A requirement of my Master's program is to undertake a research study and I have chosen to interview bereaved family caregivers about their adjustment to the loss of the person they were caring for. There is very little research in this area to help health care professionals understand what helps people as they deal with such a loss. I believe that understanding family caregivers' experiences could increase the sensitivity of health care professionals in how they respond to bereaved caregivers. It may also provide a basis for planning programs and interventions to suit the needs of family caregivers.

This letter was sent to you by a Victoria Hospice Society counsellor or Home Care nurse who thought that you might be interested. It invites you to consider participating in this study and gives you information about what is involved. I would like to interview family caregivers who are bereaved and have had an opportunity to reflect on how they have managed grief and adjusted to changes in their lives. If you agree to participate, your interviews would take about 1 to 1½ hours, scheduled at a time and place that would suit you. The interview will be tape recorded to ensure that what you have to say is recorded accurately. I may want to contact you again by phone for a second shorter interview, about 15-30 minutes, if this is agreeable to you. This interview would take place near the end of my study and clarify my understanding of your experiences and the experiences of others.

Your participation in this study is entirely voluntary and will in no way affect the care you receive from any health care services. You are free to withdraw from the study at anytime if you should wish to do so for any reason. During our interviews, you may refuse to answer any of my questions, ask for portions of the tape to be erased, or request that sensitive

information not be used in the study. At the time of the first interview, I will introduce a consent form, discuss it with you, and ask that you sign it.

Your confidentiality will be ensured in several ways. The tapes and transcripts of the interviews will be identified by a code number only and will be kept separately from your name and other biographical information. All information will be kept secure and the tapes and transcripts will be seen only by me and members of my thesis committee. To preserve the confidentiality of all participants, biographical information will be altered in any publications or presentations of the findings from this study. The information that you share with me will be used for my thesis, future publications, and professional presentations. If you are interested, I will be happy to send you a summary of my findings when the study is complete.

Thank you for considering my request. Your participation would contribute to a better understanding of the experiences of family caregivers in bereavement and to developing helpful interventions and supports.

If you think that you would like to participate, there are two ways to get connected. First, you could call me directly at 382-7671. Second, if you prefer to call _____ (the referring professional's name) at _____ (their telephone number), you can ask them about me and my research study. If you give them permission to do so, they will give your name and number to me so that I can call you.

If you want to know more about the study, please call me at 382-7671 or you may call my supervisor, Dr. Kelli Stajduhar, at 721-7487.

Sincerely,

Moira Cairns
Junior Graduate Trainee,
Michael Smith Foundation for Health Research
Master's Student,
Centre on Aging
University of Victoria



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 PO BOX 1700, STN CSC
 Victoria, British Columbia
 Canada V8W 2Y2
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 Web: <http://www.coag.uvic.ca>

Code # ____

What Helps Bereaved Family Caregivers Adjust to Their Loss *An Interpretive Descriptive Study*

Researcher: Moira Cairns, BA, RSW
 Junior Graduate Trainee
 Michael Smith Foundation for Health Research
 University of Victoria

Faculty Advisor: Kelli I. Stajduhar, RN, PhD
 New Investigator, Canadian Institutes for Health Research
 Scholar, Michael Smith Foundation for Health Research
 Assistant Professor
 School of Nursing and Centre on Aging
 University of Victoria

Letter of Invitation to Participate in a Research Project

Hello,

I am a student in the Interdisciplinary Master of Arts program at the University of Victoria. I am also a registered social worker with a background in hospice and bereavement counselling. A requirement of my Master's program is to undertake a research study and I have chosen to interview bereaved family caregivers about their adjustment to the loss of the person they were caring for. There is very little research in this area to help health care professionals understand what helps people as they deal with such a loss. I believe that understanding family caregivers' experiences could increase the sensitivity of health care professionals in how they respond to bereaved caregivers. It may also provide a basis for planning programs and interventions to suit the needs of family caregivers.

This letter was sent to you by Victoria Hospice Society group facilitator, Adaline O'Gorman, who thought that you might be interested. It invites you to consider participating in this study and gives you information about what is involved. I have interviewed family caregivers who are bereaved and have had an opportunity to reflect on how they have managed grief and adjusted to changes in their lives. I have analysed what they told me and have ideas about their experiences and what is helpful to them. I would like to bring these ideas to you in a group situation and ask for your thoughts and feedback on what I have found. This will help to ensure that my understanding of family caregivers' experiences in bereavement is clear and credible. If you agree to participate, the next

Widows' bereavement group session could be devoted to the presentation and discussion of my research study findings to this point.

Your participation in this study is entirely voluntary and will in no way affect the care you receive from any health care services. You are free to withdraw from the group and the study at anytime if you should wish to do so for any reason. During the focus group, you may refuse to answer any of my questions, ask for portions of the tape to be erased, or request that sensitive information not be used in the study. At the time of the focus group, I will introduce a consent form, discuss it with you, and ask that you sign it.

Your confidentiality will be ensured in several ways. The tapes and transcripts of the focus will be identified by a code number only and will be kept separately from your name and other biographical information. All information will be kept secure and the tapes and transcripts will be seen only by me and members of my thesis committee. To preserve the confidentiality of all participants, biographical information will be altered in any publications or presentations of the findings from this study. The information that you share with me will be used for my thesis, future publications, and professional presentations. If you are interested, I will be happy to send you a summary of my findings when the study is complete.

Thank you for considering my request. Your participation would contribute to a better understanding of the experiences of family caregivers in bereavement and to developing helpful interventions and supports.

If you think that you would like to participate, there are three ways to get connected. First, you could call me directly at 250-472-4466. Second, if you prefer to call Adaline O'Gorman at 250-592-0477, you can ask her about me and my research study. If you give her permission to do so, she will give your name and number to me so that I can call you. Third, you can come to the next Widow's bereavement group and discuss it before the focus group begins.

If you want to know more about the study, please call me at 250-472-4466 or you may call my supervisor, Dr. Kelli Stajduhar, at 250-721-7487.

Sincerely,

Moira Cairns
Junior Graduate Trainee,
Michael Smith Foundation for Health Research
Master's Student,
Centre on Aging
University of Victoria

Appendix C –Demographic Information Form

Demographic Variables for Family Caregiver NET

Study name: _____

Study ID#: _____

1a. Relationship of care recipient to caregiver. You were caring for your...

- | | |
|--|---|
| <input type="checkbox"/> Husband/wife/life partner | <input type="checkbox"/> Daughter/son |
| <input type="checkbox"/> Parent | <input type="checkbox"/> Sister/brother |
| <input type="checkbox"/> Parent-in-law | <input type="checkbox"/> Other (please specify) _____ |

1b. Did you live with the care recipient? Yes No

If yes, for how long did you live with the care recipient? _____

2a. Marital Status – caregiver

- Married or living as married
- Widowed
- Never married
- Divorced or separated and not presently remarried
- Other (please specify) _____

2b. Marital Status – care recipient

- Married or living as married
- Widowed
- Never married
- Divorced or separated and not presently remarried
- Other (please specify) _____

3a. Caregiver age _____

3b. Care recipient age _____

4a. Caregiver sex

- Male
- Female

4b. Care recipient sex

- Male
- Female

5a. Highest level of education you

Completed

- Elementary school or less
- Some high school
- High school graduate

- Some college (including CEGEP) or trade school
 - Diploma from college (including DEC) or trade school
 - Attended university
 - University degree
 - Post-graduate degree
 - Other (please specify) _____
-

6a. Caregiver ethnicity

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

6b. Care recipient ethnicity

To which ethnic or cultural groups did the care recipient or the majority of the care recipient's ancestors belong on first coming to Canada? (list more than one if necessary)

7a. What was your employment status (caregiver) at the time you were caregiving?

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

7b. Did your employment status changed as a result of your caregiving role?

- Yes No

If **yes**, what was your previous employment status?

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

7c. Occupation

8a. What was your average household income while you were caregiving? (for the purposes of this question we are interested in the caregiver's household income regardless of whether the care recipient has moved in with the caregiver or vice versa)

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

9. What was the care recipient's diagnosis? _____

10a. For how long did you provide care for the care recipient?

_____ months and _____ years

Health Questions

1. In general, would you say that your health is :

Excellent Very good Good Fair Poor

2. Compared to before _____ (patient's name) died, how would you rate your health in general now?

Much better than before.....1

Somewhat better than before.....2

About the same as before.....3

Somewhat worse than before.....4

Much worse than before.....5

3. Since _____ (patient's name) died, how much of the time has your physical health interfered with your usual activities (work, leisure activities, family activities, etc.)?

All of the time.....1

Most of the time.....2

Some of the time.....3

A little of the time.....4

None of the time.....5

4. Since _____ (patient's name) died, how much of the time have emotional problems interfered with your usual activities (work, leisure activities, family activities, etc.)?

All of the time.....1

Most of the time.....2

Some of the time.....3

A little of the time.....4

None of the time.....5

Appendix D – Interview Guide/Schedule

Interview Guide/Schedule

We have just been talking about what the study is about and the details of how it will be managed, but now I'd like to focus on you and your experiences as a bereaved person.

Tell me about your experiences since (person's name) died.

What has been difficult for you? What did you do about that?

Were there things that helped? Can you give me an example of a time when things helped?

Were there things that were not helpful? Can you give me an example of a time when things did not help?

What has gone well for you? What do think made things go well?

What do you think has influenced how you have done during this time?

There are a number of common grief reactions that people may have. I'd like to ask you about these areas of your life and your experiences. I am interested in whether there were things that helped you or did not help you. What did you experience in terms of

- your emotions?

What sort of feelings or emotions did you experience? How did you manage your feelings?

Please tell me about them and what helped or did not help with them.

- social aspects of your life?

Were there any people who were helpful to you? Please tell me about them and how they helped. Were there any people who were not helpful? Please tell me about them and how they were challenging.

- self-care?

Were there things that you were able to do for yourself that helped you? Were there things that you did that were not helpful? Can you give me an example?

Other areas for similar kinds of questions might include:

- physical reactions

Please tell me about them and what helped or did not help with them.

- your faith or philosophy of life

Please tell me about them and what helped or did not help with them.

- thoughts, memories, and dreams?

Please tell me about them and what helped or did not help with them.

Did you seek out any formal or professional help in your bereavement? For example, talk to your doctor, a counsellor, or leader of your faith community; attend a group?

Were there any things that you experienced while you were caring for (person's name) that influenced your bereavement and adjustment to your loss? Would you say they were helpful or challenging?

Appendix E – Consent Forms



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 Victoria, BC
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Code # ____

Research Study (Master's Thesis)

What Helps Bereaved Family Caregivers Adjust to their Loss

Principal Investigator: Moira Cairns, Masters' Student
 University of Victoria, Interdisciplinary Studies
 Phone: (250) 472-4466
 Email: mmcairns@uvic.ca

Co-Supervisors: Dr. Kelli Stajduhar, R.N., Ph.D.
 University of Victoria, School of Nursing
 Phone: (250) 721-7487
 Email: kis@uvic.ca

Dr. Holly Tuokko, Ph.D.
 University of Victoria, Department of Psychology
 Phone: (250) 721-6576
 Email: htuokko@uvic.ca

You are being invited to participate in a research study. As part of the requirements for my Masters degree in Interdisciplinary Studies (Psychology and Nursing), I'm conducting a research project called "What helps bereaved family caregivers adjust to their loss". It is being conducted under the supervision of Dr. Kelli Stajduhar and Dr. Holly Tuokko. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time without consequences or explanation. If you do withdraw from the study, you will be asked for your consent for me to use your input up to that point. You are free to refuse to answer any questions, can ask for any information to be destroyed, and can ask for sensitive information not to be divulged.

Purpose

The purpose of this research project is to provide insight into the bereavement experiences of family caregivers. The objectives of this research are to: (1) describe the experiences of bereaved family caregivers; (2) describe what bereaved family caregivers find helpful and unhelpful in adjusting to the loss of a significant other; and (3) to identify factors or influences that promote adjustment in bereavement for family caregivers. Knowledge from this study may contribute to the development of supportive policies and services.

Procedures

You are being asked to participate in this study because you cared for a seriously ill adult at home between one and three years. I am asking for your consent to participate in one face-to-face interview that will last approximately 1-1 ½ hours. I will use a series of guiding questions developed specifically for this study and engage in a conversation with you to learn about your experiences. I may ask to speak to you again for a second shorter interview (20-30 minutes) by phone and will review this consent form with you at that time. Interviews will be arranged at a time and location of your convenience and will be tape recorded and typed by a transcriptionist who is hired for this project. At the completion of the study you will be sent a summary of the findings.

Risks

There may be a potential risk to discussing your experiences in that these discussions may bring up unexpected grief reactions. In this instance, if you request it, we will contact the nurse or counsellor who referred you and give you information about counselling services.

Potential Benefits

You will not receive any direct benefits from participating in this study. However, it is possible that you may benefit from reviewing your personal progress in bereavement. Also, it is anticipated that the results of this research may provide important information for developing strategies to assist family caregivers in their bereavement in the future.

Monetary Compensation

There will be no monetary compensation for participating in this study.

Confidentiality

Any identifying information resulting from this study will be kept strictly confidential. All documents will be identified by only a code number and will be kept in a locked filing cabinet in Dr. Stajduhar's research office at the University of Victoria. Any computer hard drives that contain identifying information or data will be password protected. Identifying information from computer hard drives will be deleted at the end of the project.

Information contained in the transcripts from the tape recorded interviews will have all identifying information removed. There will be no reference made to individual names in reports or publications coming out of this study. In all final research reports and publications, quotes from participants will remain anonymous and, if necessary, other identifying information will be altered. At the end of the study, audiotapes will be erased. However, the typed transcripts obtained in this study will be retained indefinitely by me to be used to publish academic papers and be accessible for further analysis as part of my continuing education with the understanding that any additional research projects that use the data will be approved by the appropriate university research and ethics committees.

If you have **any questions or concerns** at any time during this study you may contact Moira Cairns (472-4466), Dr. Kelli Stajduhar (721-7487), or Dr. Tuokko (721-6576). If you have any concerns about your rights or treatment as a research participant you may contact the Associate Vice-President of Research at the University of Victoria (472-4362) or Dr. Peter Kirk, Director, Research and Clinical Development, Vancouver Island Health Authority (370-8261).

Your signature below indicates that you have read the above information and have had an opportunity to ask questions to help you understand what your participation will involve. Your signature indicates that you consent to participate in this study and that you have received a copy for this consent form for your own records.

Signature of Participant

Date

Printed name of Participant

Signature of Researcher

Date

Printed name of Researcher



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UVic

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Purpose

The purpose of this research project is to provide insight into the bereavement experiences of family caregivers. The objectives of this research are to: (1) describe the experiences of bereaved family caregivers; (2) describe what bereaved family caregivers find helpful and unhelpful in adjusting to the loss of a significant other; and (3) to identify factors or influences that promote adjustment in bereavement for family

caregivers. Knowledge from this study may contribute to the development of supportive policies and services.

Procedures

You are being asked to participate in this study because you cared for a seriously ill adult and are bereaved. I am asking for your consent to participate in one group discussion or *focus group interview* that will last approximately 1-1 ½ hours. Within the context of the bereavement support group that you attend, I will present my preliminary findings from the interviews that I have done with other bereaved family caregivers. I also will ask for your feedback on whether these findings resonate with your own experiences of bereavement. The *focus group interview* will be tape recorded and typed by a transcriptionist who is hired for this project. At the completion of the study you will be sent a summary of the resulting findings.

Risks

There may be a potential risk to discussing your experiences in that these discussions may bring up unexpected grief reactions. In this instance, if you request it, the group facilitator will be available to provide support and we will give you information about counselling services that are available to you.

Potential Benefits

You will not receive any direct benefits from participating in this study. However, it is possible that you may benefit from reviewing your personal progress in bereavement. Also, it is anticipated that the results of this research may provide important information for developing strategies to assist family caregivers in their bereavement in the future.

Monetary Compensation

There will be no monetary compensation for participating in this study.

Confidentiality

Any identifying information resulting from this study will be kept strictly confidential. All documents will be identified by only a code number and will be kept in a locked filing cabinet in Dr. Stajduhar's research office at the University of Victoria. Any computer hard drives that contain identifying information or data will be password protected. Identifying information from computer hard drives will be deleted at the end of the project.

Information contained in the transcripts from the tape recorded group interview will have all identifying information removed. There will be no reference made to individual names in reports or publications coming out of this study. In all final research reports and publications, quotes from participants will remain anonymous and, if

necessary, other identifying information will be altered. At the end of the study, audiotapes will be erased. The typed transcripts obtained in this study will be retained indefinitely by me to be used to publish academic papers and be accessible for further analysis as part of my continuing education with the understanding that any additional research projects that use the data will be approved by the appropriate university research and ethics committees.

Given that focus group interviews involve other individuals, we cannot guarantee anonymity or confidentiality. Yet, we can minimize breaches of either one by asking that you respect the anonymity and confidentiality of your fellow focus group participants and not identify the individual contributions made by other participants. We encourage all participants to refrain from disclosing the contents of the discussion outside of the focus group; however, we cannot control what other participants do with the information discussed.

If you have **any questions or concerns** at any time during this study you may contact Moira Cairns (472-4466), Dr. Kelli Stajduhar (721-7487), or Dr. Tuokko (721-6576). If you have any concerns about your rights or treatment as a research participant you may contact the Associate Vice-President of Research at the University of Victoria (472-4362) or Dr. Peter Kirk, Director, Research and Clinical Development, Vancouver Island Health Authority (370-8261).

Your signature below indicates that you have read the above information and have had an opportunity to ask questions to help you understand what your participation will involve. Your signature indicates that you consent to participate in this study and that you have received a copy for this consent form for your own records.

 Signature of Participant

 Date

 Printed name of Participant

 Signature of Researcher

 Date

 Printed name of Researcher