

# Family Caregiver Coping in End-of-Life Cancer Care

**Final Report**  
**July, 2008**

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A research project funded by:

Canadian Cancer Society through the National Cancer Institute of Canada



Canadian  
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canadienne  
du cancer



National  
Cancer Institute  
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Institut national  
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## *Transcription Support*

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## Table of Contents

Acknowledgments.....	2
Executive Summary .....	3
Background and Research Objectives.....	8
Research Approach and Methods.....	9
Data Analysis.....	10
Findings .....	10
Phase I: Qualitative Findings.....	10
Profile of Family Caregiver Participants.....	10
Factors Influencing Family Caregiver Coping .....	10
Caregiver’s Approach to Life .....	11
Patients Illness Experience .....	12
The Patient’s Recognition Of The Caregivers’ Contribution To Their Care.....	12
The Quality Of The Relationship Between The Caregiver And Dying Person .....	13
The Caregiver’s Sense Of Security .....	13
Phase II: Quantitative Findings.....	14
Profile of Family Caregiver Participants.....	14
Factors Associated with Quality of Life and Depression .....	15
Who are the Family Caregivers Most at Risk and Least at Risk for Negative Health Outcomes?.....	16
What are the Coping Strategies Used By Family Caregivers Providing End-of-Life Cancer Care? .....	17
What are the Coping Strategies Used by Family Caregivers Most at Risk and Least at Risk for Negative Health Outcomes? .....	17
Recommendations .....	18
Preparation for the Family Caregiver Role.....	18
Working with Family Caregivers .....	19
Assessing the Needs of Family Caregivers.....	19
Health Care System Improvements... ..	20
Conclusions .....	20
Appendix A: Questionnaires Used in Quantitative Survey.....	21
Appendix B: Phase I Demographics.....	24
Appendix C: Phase II Demographics.....	25
References.....	27

## ACKNOWLEDGMENTS

Completing a project such as this cannot be accomplished by any one person. The very nature of research entails the active engagement and participation of many people and organizations. We would like to gratefully acknowledge the contributions of all those who have supported this project.

The project would not have been possible without our most capable Project Coordinator and cadre of research assistants residing in each of the cities that participated. Their collective wisdom, experience, and expertise helped direct the process and shape the final analysis.

Many of the members of our research team were supported by their work places in order to become involved in this research and we would like to acknowledge the support of their agencies: Victoria Hospice Society, Fraser Health Authority, Interior Health Authority Home and Community Care and the BC Cancer Agency Centres for the Southern Interior and Vancouver Island.

We would also like to acknowledge the Canadian Cancer Society and the National Cancer Institute of Canada who provided the funding for this research project and to the Canadian Institutes of Health Research (CIHR) and the Michael Smith Foundation for Health Research (MSFHR) who fund Dr. Stajduhar through their Career Scholar programs.

Finally, we are humbly indebted to all of those people who gave their time and energy to share their experiences and who participated in this project. You have our deep admiration and respect for your strength and selflessness.

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## *Executive Summary*

In the past decade, shifts toward providing care at home to dying patients have resulted in increased demands on family caregivers (FCGs). While FCGs are willing to provide care, the burden of caregiving can exceed their capacity to cope. Family caregivers often focus on the needs of the dying person, neglecting their own physical and mental health.

Little attention has been given to the positive aspects of the caregiving experience and why some FCGs seem to manage better than others, even when they are under similar caregiving demands. This research aims to balance the emphasis on FCG burden, to examine factors that influence healthy outcomes for family members providing end-of-life cancer care at home.

The specific research objectives of this study were to:

1. Explore factors that influence family caregiver coping in end-of-life cancer care;
2. Determine the relationship between these factors and family caregiver outcomes of quality of life and depression;
3. Determine which FCGs are most at risk of negative health outcomes such as reduced quality of life and depression;
4. Determine the FCGs who, in demanding situations, nevertheless seem to manage well and are least at risk of negative health outcomes; and
5. Determine the coping strategies used by FCGs.

Our hope is that the findings from this study will be used to inform the development of health interventions directed toward FCGs having difficulties managing, who themselves may become at risk of needing health care services, and who may experience reduced quality of life, depression, and other health problems as a result of caregiving.

## *Research Design*

This was a mixed method (qualitative/quantitative), multi-site study of FCGs caring for someone with cancer at end-of-life. Data were collected in two phases and in a variety of ways. In Phase I, data were collected by: In-depth semi-structured qualitative interviews with a purposive sample of 29 FCGs currently providing end-of-life cancer care; In-depth semi-structured qualitative interviews with a purposive sample of 17 bereaved FCGs; Three focus group interviews with bereaved FCGs (n=19) and; Two focus group interviews with health care providers (n=14) to supplement data from the FCG interviews.

In Phase II, data were collected by administration of a series of questionnaires to a consecutive sample of 264 FCGs currently providing end-of-life cancer care and 53 bereaved FCGs for a total of 317 participants.

## Key Findings

### Phase I Findings

#### *Description of the Study Participants*

In Phase 1, a total of 46 FCGs participated in a face-to-face qualitative interview. Of these 46 FCGs, 29 were currently providing end-of-life care and 17 were bereaved. An additional 19 FCGs participated in one of three focus group interviews (one group in each of the study sites), for a total sample of 65 FCGs.

All participants were Caucasian with 37% identifying as of European descent. The average age was 62 years, 66% were caring for their spouse or partner and 47% were retired. Providing care at home carried a substantial workload with 62% of participants stating they provided care more than 40 hours per week. The dying person had a variety of cancer diagnoses (as reported by the FCG): 19% had gastrointestinal cancer, 17% lung cancer, 14% breast cancer or cancer of the female sex organs, 14% brain cancer, 11% prostate and, 25% various other types of cancers such as esophageal, pancreatic, melanoma and myeloma.

#### *Factors Influencing Family Caregiver Coping*

Based on our analysis from the qualitative interviews of there were five factors that influenced FCGs' ability to cope including the following:

- (1) The caregiver's approach to life where a "just do it" attitude enabled them to get on with the task at hand. These FCGs described themselves as organized, confident and easily able to take control of a situation.
- (2) The patient's illness experience was important because when the patient was doing well and symptoms were controlled, then the FCG reported doing well. The patient's outlook on the illness also influenced the FCG's ability to cope.
- (3) The patient's recognition of the caregivers' contribution to their care meant the dying person did not take the FCG for granted and treated the FCG in a respectful manner. The patient who was a "good patient", cooperating with various aspects of care motivated the FCG to continue providing home care.
- (4) The quality of the relationship between the caregiver and dying person influenced the ability of the FCG to cope. Strong relationships often became closer while strained relationships continued to be so and at times deteriorated.
- (5) The caregiver's sense of security meant there was a structure in place to support them in coping with their caregiving role. Family and friends who were non-judgemental and available to provide practical help, as well as having access to relevant and timely information contributed to a secure environment. Knowing the health care system would be there to support them when they most needed it was important.

### Phase II Findings

#### *Description of the Study Participants*

In Phase 2, 317 FCGs completed the full set of questionnaires. Of these 317, 83% were currently providing care and 17% were bereaved. Most participants were Caucasian with 83% identifying as of European descent. English was not always the first language of all participants with 22%

..... *Family Caregiver Coping in End-of-Life Cancer Care*

reporting being born outside of Canada. These FCGs had an average age of 58 years, 52% were caring for their spouse and 41% were retired. Over 53% were providing care for more than 50 hours per week. The dying person had a variety of cancer diagnoses (as reported by the FCG): 22% had lung cancer, 17% breast or cancers of the female sex organs, 16% gastrointestinal cancer, 8% prostate cancer, 6% renal cancer, 5% lymphoma, 4% brain cancer and 22% had various other types of cancers such as esophageal, pancreatic, melanoma and myeloma.

*Factors Associated with Quality of Life and Depression*

We chose quality of life and depression as our two main outcome variables because reduced quality of life and depression are reported to be indicators of how well a family member manages with the sometimes heavy demands of family caregiving.

The general trend seems to suggest that increased depressive symptoms and reduced quality of life were found in FCGs who were younger, and who reported: decreased levels of optimism, resilience and sense of coherence; greater role interference or disruption to their regular routine; dissatisfaction with the quality of health care received; feeling unprepared for the caregiving role; having increased levels of burden; caring for patients with greater symptoms and those with a cognitive impairment; and where the relationship between the patient and FCG was reported to be poor.

*Who are the Family Caregivers Most at Risk and Least at Risk for Negative Health Outcomes?*

We were interested in identifying the FCGs most at risk for negative health outcomes as we believed that such an understanding could help to identify those FCGs who might be in the most need of support from the health care system. We are not suggesting that only those FCGs most at risk should receive service as almost all of the FCGs who participated required some level of support from the health care system. We also know, from our qualitative data, that needs change over the course of the caregiving experience and that family caregiving is an inherently complex process that cannot be fully quantified. We did, however, think that identifying FCGs most at risk could potentially “red flag” those FCGs who might get into trouble so that we could engage in anticipatory planning to prevent or alleviate any potential crises or health risks.

Based on our analysis, those most at risk for negative health outcomes are more likely to be: younger females with a lower income, who are employed or are taking a paid or unpaid leave from work and who are caring for a parent; and who have: lower levels of resilience and optimism, greater stress and report less sense of coherence. These FCGs also reported feeling: less prepared for the caregiving role and reported lower levels of family functioning.

Similarly, those least at risk for negative health outcomes are more likely to be: older retired females who are caring for their partner, had higher than average incomes and reported fewer financial worries; and who have: higher levels of resilience, optimism, sense of coherence and family functioning. These FCGs also reported: low levels of stress and felt more prepared for the caregiving role.

*What are the Coping Strategies Used By Family Caregivers Providing End-of-life Cancer Care?*

Finally, we were interested in understanding what coping strategies were used by FCGs. The three most prominent ways of coping reported by FCGs in this study were: (1) planful problem-solving; (2) seeking social support; and (3) self-controlling. Those least at risk used (1) planful problem solving; (2) Self controlling; and (3) seeking social support. Those most at risk used (planful problem solving; (2) escape-avoidance; and (3) seeking social support.

## *Recommendations*

Recommendations contained in this report arise from the research team’s interpretation of the data and include those elements that study participants suggested are needed. In addition to what FCGs advised we also engaged in a series of discussion groups with front-line health care providers, managers and decision makers that occurred in each of the three study sites. Almost 70 people participated in these discussions. Through this process, and our own understanding of the study results, we make the following recommendations.

### *Preparation for the Family Caregiver Role*

Family caregivers are clearly an essential part of the health care system. Their involvement in the care of the dying person is necessary, and in most cases, required, to adequately maintain the dying person at home. Our findings suggest that being as prepared as possible to take on the role of FCG is an important component of maintaining quality of life and reducing potential health problems.

Taking a more active approach to preparing FCGs for the caregiving role, should they desire this, is an important intervention that health care providers can offer. Guidance on the practical aspects of caregiving seems to be important to FCGs such as lifting and transferring people safely; how to manage pain and appetite changes; how to toilet and bath people in bed; and how to work with family and friends to communicate the help that they can offer. Family caregivers reported that providers make assumptions about their practical knowledge base, assuming that the FCG knows and understands what is involved in providing the practical aspects of care. Family caregivers said such assumptions are erroneous and asked that providers not assume their knowledge base and teach them about the practical aspects of care.

Many FCGs find the provision of information to be important but say that they are often overwhelmed by the amount of information in addition to the timing of when it is delivered. The individualization of information should be considered as opposed to a ‘standard’ way of providing information to all FCGs.

### *Working with FCGs*

Recognizing and appreciating their efforts can help FCGs to feel better able to cope with the demands of caregiving. This can be done by openly recognizing the valuable contributions that FCGs make to the health care system and to the care of the dying person.

Family caregivers spoke of the important role that family and friends can have in supporting their caregiving experience. What was most important to them were offers of practical hands-on help and having support systems available that were non-judgemental. At the same time, many FCGs find it difficult to ask for help or to deal with help from family and friends that is unsupportive. Health care providers can play a role in helping FCGs negotiate such help and offer advice to extended family and friends on ways to help the FCG.

Home care nurses are often the primary care providers to families in palliative care. Within the context of palliative care, many psychosocial issues arise and where available, nurses often call upon social work colleagues for assistance. However, social work assistance is not always available and some FCGs are reluctant to accept help from them. Where social work service is available, there is often pronounced role differentiation between nurses and social workers. In some instance, role conflict has resulted in FCGs not getting the support that is needed. Many



participants acknowledged that the nursing-social work team works well if the roles are blended. Such a blending works well to meet the needs of FCGs as they appear more receptive to social work assistance once it is introduced and supported by the nurse. In instances where social work service is not available or inadequate, however, education to assist home care nurses to feel comfortable in working with psychosocial issues may be warranted.

***Assessing the Needs of Family Caregivers***

In order to prevent negative health outcomes, an assessment of FCG needs is required. While in theory FCGs are an important component of the unit of care in palliative care, in practice, many FCGs say that their needs are not considered to the extent that they likely should be; they are important proxies for reporting patient related issues, but as people with legitimate needs of their own, they are often not given the same consideration as the person who is dying.

Providers asked if we might suggest an assessment tool that would be useful in identifying those FCGs at risk for negative health outcomes. In this study we identified a number of indicators for those most at risk that could be used as “red flags” to indicate those FCGs who might be in need of assistance. At the same time, assessing traits such as resilience, optimism and stress can be a timely process that in practice, may not be realistic to complete given clinician time constraints. The development of a quick, practical FCG assessment tool that was sensitive to identifying FCGs who may be susceptible to negative health outcomes would be useful in practice and having such a tool validated through research would provide reliable, valid assessment information.

***Health Care System Improvement***

While our study did not explicitly address health care system improvements, many FCGs had advice about the kinds of things that would be helpful to them in coping with the demands of caregiving. Having access to specialized palliative care services 24 hours a day, 7 days a week was a recommendation that came forward often. While 24 hour access to a call centre, such as the BC Nurse Line was seen as helpful, FCGs said that speaking with someone who knew something about their case and about palliative care was most helpful to them.

The delivery of home support was an issue that arose in almost every interview with FCGs and in our discussion groups. The home support system, to a large degree, is simply not working well to meet the needs of families in palliative care. Inconsistent care workers, their varying degrees of educational preparation and the absence of night service were issues repeatedly mentioned that need to be resolved. Family caregivers and providers claim that resolution of these issues would bring about the most significant improvements to the care system.

Finally, FCGs are better able to manage the demands of caregiving when the dying person is well taken care of. Management of pain and other distressing symptoms is of primary importance to FCGs and continued efforts to improve the delivery of palliative care to prevent unnecessary suffering should be a goal of any health care system. Education for providers and resources to support effective support for patients and families will do much to enhance the quality of life of FCGs. The fact that dissatisfaction with the quality of health care received was an important factor associated with reduced quality of life and increased depression among FCGs points to a need to further explore system issues that are in need of improvement to enhance care for dying people and their family members.

## *Family Caregiver Coping in End-of-life Cancer Care*

### *Background and Research Objectives*

In the past decade, shifts toward providing care at home to dying patients have resulted in increased demands on family caregivers (FCGs). Despite FCGs' willingness to provide care, research suggests the burdens associated with caregiving often greatly exceed FCGs capacity to cope<sup>1</sup>. Many family caregivers neglect their own physical and mental health, focusing only on the needs of the dying person<sup>2 3</sup>. A growing body of evidence suggests that up to one-third of palliative caregivers exhibit depressive symptomatology and other mental and physical problems that may affect their long-term health<sup>4 5 6 7 8</sup>.

While much attention has been placed on the deleterious effects of caregiving on family members of the dying, little attention has been given to the positive aspects of the caregiving experience<sup>9</sup>. There has been surprisingly little research examining why some FCGs seem to manage better than others, even when they are under similar caregiving demands. This research aims to balance the emphasis on FCG burden, to examine factors that influence healthy outcomes for family members providing end-of-life cancer care at home.

The specific research objectives of this study were to:

1. Explore factors that influence family caregiver coping in end-of-life cancer care;
2. Determine the relationship between these factors and family caregiver outcomes of quality of life and depression;
3. Determine which FCGs are most at risk of negative health outcomes such as reduced quality of life and depression;
4. Determine the FCGs who, in demanding situations, nevertheless seem to manage well and are least at risk of negative health outcomes; and
5. Determine the coping strategies used by FCGs.



Our hope is that the findings from this study will be used to inform the development of health interventions directed toward FCGs having difficulties managing, who themselves may become at risk of needing health care services, and who may experience reduced quality of life, depression, and other health problems as a result of caregiving.

By better understanding the components that are associated with positive appraisal of caregiving, we will be in a better position to build on the strengths of FCGs, ameliorate some of the negative consequences that can result from caregiving, devise strategies to help FCGs in their role, and prevent the potential social and economic costs associated with family caregiver burnout.

## *Research Approach and Methods*

This was a mixed method (qualitative/quantitative), multi-site study. The study took place in three urban centres in Western Canada, all with well-established palliative care services. Data were collected in two phases and in a variety of ways.

In Phase I, data were collected by:

- ♦ In-depth semi-structured qualitative interviews with a purposive sample of 29 FCGs currently providing end-of-life cancer care;
- ♦ In-depth semi-structured qualitative interviews with a purposive sample of 17 bereaved FCGs<sup>i</sup>;
- ♦ Three focus group interviews with bereaved FCGs (n=19); and
- ♦ Two focus group interviews with health care providers (n=14) to supplement data from the FCG interviews.

In Phase II, data were collected by:

- ♦ Administration of a series of questionnaires (see Appendix A for a complete list of questionnaires) to a consecutive sample of 264 FCGs currently providing end-of-life cancer care and 53 bereaved FCGs<sup>ii</sup> for a total of 317 participants.

To be eligible for *qualitative interviews*, FCGs had to be people who (a) were currently providing care at home to an adult diagnosed with advanced cancer<sup>iii</sup>, for whom the goal of cure was no longer reasonable and the primary goal of treatment was palliative, and who (b) had a life expectancy of approximately 6 months or less. Additionally, FCGs would (c) be at least 18 years old, (d) speak English, and (e) reside in the study cities.

Eligibility for *quantitative interviews* were the same as those outlined above but because we were interested in why some FCGs seem to manage better than others even when they are under similarly heavy demands, one additional eligibility criteria – the FCG spends at least 10 hours/week as the primary FCG to the patient – was added to the eligibility criteria to operationalize similarly heavy demands.

Family caregivers were recruited in each study site by health care providers (HCPs) who explained the study and provided written information on the purpose of the study and study procedures. For Phase I, FCGs were approached if they were eligible. . Similar methods were used for Phase II, however, records of consecutive patients were kept to enhance the generalizability and quality of the study and to identify potential reasons for those who were unable to participate. Bereaved FCGs participating in focus groups were recruited through bereavement support groups and recommendations from HCPs. Health care providers were recruited for focus groups through a direct letter of invitation.

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<sup>i</sup> We had not originally planned to conduct one-to-one interviews with bereaved FCGs. However, some FCGs became bereaved over the course of our contact with them and desired to participate. The knowledge garnered from these interviews has added extensively to our understanding of family caregiver coping in end-of-life cancer care.

<sup>ii</sup> Although we originally intended to only interview FCGs who were currently providing care in Phase II, some FCGs became bereaved over the course of our contact with them. For these bereaved FCGs who desired to do so, we invited their participation in the study (n=53).

<sup>iii</sup> Eligibility criteria for bereaved FCGs was the same as for current FCGs, however interviews with bereaved FCGs were also done with people who had heard about the study and contacted the Principal Investigator, wanting to share the story of their experience. They were included if they cared for an adult with advanced cancer at home.

## **Data Analysis**

An interpretive thematic analysis<sup>10</sup> was completed on all qualitative data. As these data were collected, they were transcribed and checked for accuracy against the taped recordings. Transcripts were read over several times to identify recurring themes and illustrative examples from the data were highlighted. As more data were collected and reviewed, coding categories were revised and refined.

For the purpose of this report, standard univariate and bivariate statistics such as means and correlations are used to report on all quantitative data and to examine the associations among variables. More in-depth multivariate analyses are currently ongoing and will be reported in future peer-reviewed publications.

## *Findings*

We begin our discussion of study findings by focusing on Phase I qualitative findings which describe factors that influence family caregiver coping in end-of-life cancer care. Following presentation of these data, we then report Phase II quantitative findings.

### **Phase I: Qualitative Findings**

#### **Profile of Family Caregiver Participants**

In total, 46 FCGs participated in a face-to-face qualitative interview. Of these 46 FCGs, 29 were currently providing end-of-life care and 17 were bereaved. An additional 19 FCGs participated in one of three focus group interviews (one group in each of the study sites), for a total FCG sample of 65 in Phase I.

All participants were Caucasian with 37% identifying as of European descent. The average age was 62 years, 66% were caring for their spouse or partner and 47% were retired. Providing care at home carried a substantial workload with 62% of participants stating they provided care more than 40 hours per week. The dying person had a variety of cancer diagnoses (as reported by the FCG): 19% had gastrointestinal cancer, 17% lung cancer, 14% breast cancer or cancer of the female sex organs, 14% brain cancer, 11% prostate and, 25% various other types of cancers such as esophageal, pancreatic, melanoma and myeloma. Full demographics are reported in Appendix B.

#### **Factors Influencing Family Caregiver Coping**

One of the primary purposes of exploring factors that influence FCG coping was to inform our decisions about which topics to study in Phase II. Therefore, our intent was to expand on what we already knew from existing literature and to determine if there were other variables to consider for our study.

Based on our analysis from the qualitative interviews, there were five factors that influenced FCGs' ability to cope including<sup>iv</sup>:

- (1) the caregiver's approach to life;
- (2) the patient's illness experience;

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<sup>iv</sup> See Stajduhar, K.I., Martin, W., Barwich, D., & Fyles, G. (2008). Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home. *Cancer Nursing*, 31(1), 77-85.

- (3) the patient’s recognition of the caregivers’ contribution to their care;
- (4) the quality of the relationship between the caregiver and dying person; and
- (5) the caregiver’s sense of security.

**1. Caregiver’s Approach to Life**

Many of the caregivers described having an “approach” to life that enabled them to cope with providing care at home. Caregivers mentioned a “just do it” attitude that enabled them to get on with the task at hand. These caregivers described themselves as organized, confident and easily able to take control of a situation.

The unpredictability of the cancer illness trajectory and the realization that their loved one would eventually die was difficult for some caregivers to cope with. Because of this, caregivers took things “one day at a time”. Taking things one day at a time allowed caregivers to cherish each day that they had with the patient and not get discouraged by the realities that lay ahead.

*“I guess [I] just take one day at a time. Just take one day at a time and don’t think too far ahead. Think positive and don’t get discouraged. It doesn’t matter how bad it gets, try not to get discouraged. And sometimes it doesn’t matter how hard you try. We all think that we can do it [caregiving at home] and we all think that we are strong. But sometimes, you break down.”*

Caregivers who described themselves as coping well with providing end-of-life cancer care at home had the internal resources to cheer themselves on despite the challenges they faced. Even when the work associated with caregiving became overwhelming, these caregivers were able to re-frame their thinking in order to carry on.

*“I kept telling myself, “I can’t, I can’t, I can’t” [do the work associated with caregiving]. And everyday I’d get up and I’d go, “I can’t.” The next day, I’d go to bed at night and say, “Yes you can”. Tomorrow is a new day. You’ve got to get up. Change your attitude. Get outside where you are, in that darkest place.”*

Despite relatively positive attitudes displayed by many FCGs in this study, there were some FCGs who did not enjoy the caregiving role, but viewed it as something they “had to do” and that they “couldn’t walk away from”. These caregivers felt obligated to provide care, not only because they did not want to abandon their loved one in a time of need, but also because they wanted to contribute to a health care system that they perceived to be in need of help. One caregiver mentioned not wanting to “shirk” his responsibilities of caring for his brother, suggesting that he could help an overburdened health care system by not placing his brother in an institution.

Caregivers who expressed a positive approach to life tended to describe their caregiving experiences in a positive way and seemed to cope well with the caregiving situation. These caregivers were able to:

- ♦ recognize their limitations;
- ♦ seek advice and help with caregiving early in the patient’s disease trajectory and before they became overburdened; and
- ♦ realize that advance preparation was important if they were to continue coping.

## **2. Patients Illness Experience**

When asked about the factors that influence their ability to cope, most caregivers said that if the patient was “doing well”, they were better able to cope. Caregivers defined the dying person as “doing well” when:

- ♦ the patient’s symptoms, such as pain and nausea, were well controlled;
- ♦ the patient had a healthy appetite and was eating; and
- ♦ the patient was cognitively intact and could communicate their needs.

*“If he’s better, then I’m much better too. I think that’s probably why I’ve been coping quite well.”*

The patients’ outlook on the illness also influenced caregivers’ ability to cope. Many caregivers commented that coping with caregiving was much easier when the patient was aware of and accepting of their illness. There were times, however, when the patient had difficulties facing their illness and while most caregivers understood the patient’s anger and frustrations, dealing with these emotions made coping with the caregiving situation challenging.

## **3. The Patient’s Recognition Of The Caregivers’ Contribution To Their Care**

Some of the caregivers felt better able to cope with the demands of caregiving when their loved one recognized and appreciated their caregiving efforts. When the dying person did not take the caregiver for granted and treated the caregiver in a respectful manner, caregivers were motivated to continue providing home care. In these situations, caregivers often referred to the dying person as a “good patient” who not only recognized their contributions but was cooperative with various aspects of care. Caregivers also appreciated when the dying person realized that they needed a break.

*[I said to my husband], “Okay, you are fine for awhile. I’m going to have an out. I’m going to take a small bike ride in the park... And he’d be quite okay with that. He said, “I promise I won’t do anything. I’ll sit here and I’ll wait until you come back”. I trusted him in this way. He was sensible enough to have the sense to not do anything stupid like that [getting up by himself] ... So in that way, I was really able to get a break.”*

Some caregivers admitted that the dying person did not always treat them respectfully or recognize their caregiving contributions. These caregivers found it challenging when they perceived the dying person to be overly dependent on them. The caregivers realized that such dependency often stemmed from anxieties that the dying person had or from a fear of being left alone. Nevertheless, some caregivers felt resentful that the patient did not understand what they were going through and grieved over the loss of the person that once was.

*“Resentment was part of [how I was feeling]. She [dying mother] didn’t understand what I was going through. She wasn’t my mom anymore. She wasn’t the person that I’ve known all my life. She’s a sick, dying, weak, dependent person. And that’s not my mom. She’s not able to give. Relationships are always give and take.”*



#### **4. The Quality Of The Relationship Between The Caregiver And Dying Person**

Many caregivers talked about their relationship with the dying person and how this influenced their ability to cope. The illness can change the nature and quality of the relationship between the caregiver and dying person. Sometimes the illness makes people realize how much they appreciate one another and can make the relationship stronger. As one husband said: “I think we’re a little closer. We’re talking more about personal things than we did before. Things we used to take for granted”. Other caregivers said that their relationship with the dying person had been built on mutual love and respect and that these relationship qualities continued to be present throughout the illness. These relationships had a “give and take” quality whereby, as one wife caregiver said, “If the tables were turned, I know he would do it [caregiving at home] for me.” Knowing that such reciprocity existed made coping with caregiving much easier for these caregivers.

The illness does not always affect the quality of the relationship in a positive way, nor are all relationships built on mutual love and respect. Some caregivers explained that their relationship with the dying person had always been strained and continued to be so. In some cases, the relationship deteriorated. Because the caregivers’ ability to cope is so closely tied to both the patient’s outlook and their reaction to the illness, further difficulties that arose between the caregiver and patient made the situation even more difficult to cope with. Some caregivers felt like they were constantly “walking on eggshells”, felt nervous in their communications with the dying person, and “guarded” in everything that they did around the patient. Other caregivers confessed that they hid their emotions from the patient because as one wife said, “When he sees me crying, he just gets mad at me [and says], “what the hell’s the matter with you? It’s not you that’s got this problem, it’s me”. These caregivers lived their lives in a tenuous manner, always needing to be careful of what they said and how they spoke.



*“I basically live on the edge right now. I’m sitting on this little log, and I’m going along, or walking along and I’ve just got to be careful which way I turn because I could go right into a quagmire, if I say the wrong word.”*

Some caregivers described emotionally challenging situations, such as constantly being blamed for all that was wrong with the patient. These caregivers conceded that caregiving had become increasingly stressful and difficult for them, and in some instances, hospitalization of the patient was required to reduce the stress of the caregiver.

#### **5. The Caregiver’s Sense Of Security**

Caregivers spoke of the importance of having a structure in place to support them in coping with their caregiving role. There were several things that caregivers mentioned that were an important part of their structure and gave them a sense of security in their roles. These included:

- ♦ having family and friends available to listen in a non-judgmental manner;
- ♦ having family and friends available to provide practical hands-on help;

..... **Family Caregiver Coping in End-of-Life Cancer Care**

- ♦ having access to relevant and timely information that was presented in a logical and coherent manner (such as information on how to care for the patient (e.g., bathing, toileting, feeding, managing pain, and the health and social services that were available to them); and
- ♦ having reassurance that the health care system would be there to support them when they most needed it.

*“She [nurse] phones and says, “Well, how are the things?” I think it does help because you’re not alone. You feel like there is somebody there if you need them. If you need the help, there is help there. I think that makes it quite a lot [of difference to my coping]. Yes it does ... There’s somebody else that cares, you know ... If I need something, I can phone and I’ll have help. I’m not the person to phone just for anything. If it’s something really serious, then of course I’ll either phone or I’ll take him to the hospital. But it’s there. It’s a security more than anything. It’s a security. That’s the word for it. It’s a security.”*

Prompt response by and practical help from health care providers at the time of unpredictable patient events helped caregivers to continue coping with the demands of home-based care. Knowing that they were not alone in their caregiving journey and that help was a phone call away was more important to some caregivers than having health care providers physically present.

**Phase II: Quantitative Findings**

As previously stated, the primary aim of Phase I was to inform our decisions about the kinds of topics to study in Phase II. Findings from Phase I, along with a review of existing research, suggested that a number of variables might be important to consider in a study related to family caregiver coping in end-of-life cancer care.

In addition to using quality of life and depression as our two main outcome variables of interest, we included a number of other variables listed in Table 1 under the categories of (a) personality characteristics; (b) family functioning; (c) family caregiving experience; and (d) patient illness experience.

**Table 1. Variables in Analysis**

Personality Characteristics	Family Functioning	Family Caregiving Experience	Patient Illness Experience
Resilience Stress Optimism Sense of Coherence Ways of Coping	Family Hardiness Quality of Relationship between caregiver and patient	Burden Satisfaction with health care Role interference Preparation for Caregiving Family Caregiver Health	Functional Ability Cognitive Ability Symptom Experience

*Note: A full listing of the questionnaires used to measure these variables can be found in Appendix A.*

**Profile of Family Caregiver Participants**

Once Phase I was completed, Phase II FCG participants were recruited. In Phase II, we screened 3100 patients to identify eligible FCG participants. Of the 3100 screened, 906 (29%) met the eligibility criteria and were invited to participate. Of these 906, 337 agreed to participate, for a response rate of 37%. Reasons for non-participation included:



..... *Family Caregiver Coping in End-of-Life Cancer Care*

- ♦ FCGs stated they were too busy to participate or that things were too hard for them to be involved with the study;
- ♦ Patients were in a crisis or had a rapidly declining condition that prevented the FCG from participating;
- ♦ FCGs stated they were not interested in participating; and
- ♦ FCGs stated various other reasons for not participating including their own poor health, social issues, not feeling ready to consider the patient to be palliative, and hospitalization of the patient.

Of the 337 FCGs who participated, 317 completed the full set of questionnaires. Of these 317, 83% were currently providing care and 17% were bereaved. Most participants were Caucasian with 83% identifying as of European descent. English was not always the first language of all participants with 22% reporting being born outside of Canada. These FCGs had an average age of 58 years, 52% were caring for their spouse and 41% were retired. Over 53% were providing care for more than 50 hours per week. The dying person had a variety of cancer diagnoses (as reported by the FCG): 22% had lung cancer, 17% breast or cancers of the female sex organs, 16% gastrointestinal cancer, 8% prostate cancer, 6% renal cancer, 5% lymphoma, 4% brain cancer and 22% had various other types of cancers such as esophageal, pancreatic, melanoma and myeloma. Full demographic details of Phase II participants are in Appendix C.

*Factors Associated with Quality of Life and Depression*

We chose quality of life and depression as our two main outcome variables because reduced quality of life and depression are reported to be indicators of how well a family member manages with the sometimes heavy demands of family caregiving<sup>11 12 13</sup>.

Based on our correlational analysis examining the association between the variables in Table 1 (above) as well as demographic characteristics, we found the following to be associated with reduced quality of life and greater depressive symptoms and listed them here from the most highly correlated to those least correlated.

***Reduced quality of life was associated with:***

- ❖ Increased feelings of burden
- ❖ Increased amount of role interference
- ❖ Increased levels of FCG stress
- ❖ Decreased levels of sense of coherence
- ❖ Increased depressive symptoms of the FCG
- ❖ Dissatisfaction with the quality of health care received
- ❖ Increased number of patient symptoms
- ❖ Decreased levels of optimism
- ❖ Increased levels of cognitive impairment in the patient
- ❖ FCG reporting a poor quality relationship with the patient
- ❖ Feeling unprepared for the caregiving role
- ❖ Being younger

***Greater depressive symptoms were associated with:***

- ❖ Lower income
- ❖ Increased amount of role interference
- ❖ Decreased levels of sense of coherence
- ❖ Increased feeling of burden
- ❖ Decreased levels of FCG resilience
- ❖ Decreased levels of FCG optimism
- ❖ Increased number of patient symptoms

..... *Family Caregiver Coping in End-of-Life Cancer Care*

To summarize, the general trend seems to suggest that increased depressive symptoms and reduced quality of life were found in FCGs who were younger, and who reported:

- ♦ Decreased levels of optimism, resilience and sense of coherence;
- ♦ Greater role interference or disruption to their regular routine;
- ♦ Dissatisfaction with the quality of health care received;
- ♦ Feeling unprepared for the caregiving role;
- ♦ Having increased levels of burden;
- ♦ Caring for patients with greater symptoms and those with a cognitive impairment; and
- ♦ Where the relationship between the patient and FCG was reported to be poor.

*Who are the Family Caregivers Most at Risk and Least at Risk for Negative Health Outcomes?*

The data presented above provide a relatively clear picture of the associations between a number of variables and FCG quality of life and depression. From this, we were then interested in identifying the FCGs most at risk for negative health outcomes as we believed that such an understanding could help to identify those FCGs who might be in the most need of support from the health care system. We are not suggesting that only those FCGs most at risk should receive service as almost all of the FCGs who participated required some level of support from the health care system. We also know, from our qualitative data, that needs change over the course of the caregiving experience and that family caregiving is an inherently complex process that cannot be fully quantified. We did, however, think that identifying FCGs most at risk could potentially “red flag” those FCGs who might get into trouble so that we could engage in anticipatory planning to prevent or alleviate any potential crises or health risks.

We defined FCGs as being most at risk when they scored in the bottom quartile of both the quality of life and depression measures (i.e., low quality of life and high level of depressive symptoms). Of the 317 participants, 41 met these criteria and were considered most at risk. For comparative purposes, we were also interested in those who appeared least at risk to see if we were able to learn something about those FCGs who seemed to be managing well. Similar to above, we defined FCGs as being least at risk when they scored in the top quartile of both the quality of life and depression measures (i.e., high quality of life and low level of depressive symptoms). Despite having similar caregiving demands, of the 317 FCG participants, there were 38 participants who met these criteria.

Based on our analysis, those most at risk for negative health outcomes are more likely to be:

- Younger females with a lower income, who are employed or are taking a paid or unpaid leave from work and who are caring for a parent; and who have:
- Lower levels of resilience and optimism, greater stress and report less sense of coherence. These FCGs also reported feeling:
- Less prepared for the caregiving role and reported lower levels of family functioning.

Similarly, those least at risk for negative health outcomes are more likely to be:

- Older retired females who are caring for their partner, had higher than average incomes and reported fewer financial worries; and who have:
- Higher levels of resilience, optimism, sense of coherence and family functioning. These FCGs also reported:
- Low levels of stress and felt more prepared for the caregiving role.

***What are the Coping Strategies Used By Family Caregivers Providing End-of-life Cancer Care?***

Finally, we were interested in understanding what coping strategies were used by FCGs. We used the Ways of Coping questionnaire (See Appendix A) to better understand the strategies, thoughts and actions that people use to deal with the demands of stressful situations. This questionnaire measures eight different ways of coping. Table 2 below lists these ways of coping and provides an example of each.

**Table 2: Ways of Coping**

Confrontive	“Stood my ground and fought for what I wanted”
Distancing	“Went on as if nothing had happened”
Self-controlling	“I tried to keep my feelings to myself”
Seeking social support	“Talked to someone to find out more about the situation”
Accepting responsibility	“I apologized or did something to make up”
Escape-avoidance	“Had fantasies or wished about how things might turn out”
Planful problem-solving	“I made a plan of action and followed it”
Positive reappraisal	“Rediscovered what is important in life”

The three most prominent ways of coping reported by FCGs in this study were:

- (1) planful problem-solving;
- (2) seeking social support; and
- (3) self-controlling

***What are the Coping Strategies Used by Family Caregivers Most at Risk and Least at Risk for Negative Health Outcomes?***

Using the methods to identify those most and least at risk as described above, we were interested in determining the top three coping strategies used by those most and least at risk. Table 3 highlights the results of our analysis.

**Table 3. Coping Strategies Used by those Most and Least at Risk**

Most At Risk	Least At Risk
<ul style="list-style-type: none"> <li>1. Planful Problem Solving</li> <li>2. Escape-Avoidance</li> <li>3. Seeking Social Support</li> </ul>	<ul style="list-style-type: none"> <li>1. Planful Problem Solving</li> <li>2. Self Controlling</li> <li>3. Seeking Social Support</li> </ul>

## RECOMMENDATIONS

These recommendations arise from the research team’s interpretation of the data and include those elements that study participants suggested are needed. In addition to what FCGs advised we also engaged in a series of discussion groups with front-line health care providers, managers and decision makers that occurred in each of the three study sites. Almost 70 people participated in these discussions. Participants received a copy of preliminary study findings prior to the group meeting and were asked to comment on the implications of these findings and the strategies they felt would work to support FCGs in their everyday practice. Thus, through this process, and our own understanding of the study results, we make the following recommendations.

### *Preparation for the Family Caregiver Role*

Study findings confirm that FCGs are clearly an essential part of the health care system. Their involvement in the care of the dying person is necessary, and in most cases, required, to adequately maintain the dying person at home. Our findings suggest that being as prepared as possible to take on the role of FCG is an important component of maintaining quality of life and reducing potential health problems. Taking a more active approach to preparing FCGs for the caregiving role, should they desire this, is an important intervention that health care providers can offer; The earlier that this preparation occurs, the more prepared FCGs say they feel. Working closely with families at an early stage of their caregiving experience can help to develop relationships, enhance feelings of security and offer better opportunities for assessing the needs of the family unit.

Many FCGs acknowledged that they are not always ready for certain preparatory information (such as what to expect as a death approaches). However, they are almost always ready to learn about the practical aspects of caregiving such as lifting and transferring people safely; how to manage pain and appetite changes; how to toilet and bath people in bed; and how to work with family and friends to communicate the help that they can offer. Many of the FCGs reported that providers make assumptions about their practical knowledge base, assuming that the FCG knows and understands what is involved in providing the practical aspects of care. Family caregivers said such assumptions are erroneous and asked that providers not assume their knowledge base and teach them about the practical aspects of care.

In our effort to help FCGs be prepared for the caregiving role, information is often delivered in an overwhelming manner. Different methods of information delivery may be helpful. There are a number of caregiving manuals, electronic resources, and on-line chat groups. The challenge is to get the right information to the FCG when they need it and an individualized approach is likely to have the best effect. Having a list of reliable websites may help for people who choose to find information sources this way. As stated, practical help is often what is needed. Teaching on practical aspects of providing care is sometimes done with FCGs but there is a need to reinforce the teaching, in the form of short video clips or some method to review what teaching may have occurred with the provider. Consideration could be given to having volunteers involved in such preparatory education and reinforcement, however volunteer resources need to be considered carefully.

**Working with Family Caregivers**

Many FCGs talked about or implied a number of things that health care providers could do to help them in managing the demands of caregiving. The patient’s recognition of the caregivers’ contribution to their care can be a great motivation for the FCG to continuing to provide care at home. When FCGs feel appreciated for their efforts, both by the dying person and health care providers, they feel better able to cope with the demands of caregiving. Health care providers can do much to facilitate such recognition, simply by recognizing FCGs themselves, and also encouraging the dying person to do the same.

Family caregivers spoke of the important role that family and friends can have in supporting their caregiving experience. What was most important to them were offers of practical hands-on help and having support systems available that were non-judgemental. At the same time, many FCGs find it difficult to ask for help or to deal with help from family and friends that is unsupportive. Health care providers can play a role in helping FCGs negotiate such help and offer advice to extended family and friends on ways to help the FCG. For instance, encouraging extended family and friends to participate in practical activities such as yard work, housework, grocery shopping, and preparing meals can, if welcomed by the FCG, alleviate some of the burdens associated with caregiving. Similarly, offering to stay with the dying person to give the FCG a break or to sleep over night so that the FCG can get some much needed sleep can do much to re-energize FCGs to move forward. Encouraging or helping FCGs create “to do” lists is also a helpful strategy so the FCG does not have to continually repeat their need for support.

Home care nurses are often the primary care providers to families in palliative care. Within the context of palliative care, many psychosocial issues arise and where available, nurses often call upon social work colleagues for assistance. However, social work assistance is not always available and some FCGs are reluctant to accept help from them. Our discussion group conversations revealed that some home care nurses are uncomfortable in dealing with psychosocial issues. Additionally, where social work service is available, there is often pronounced role differentiation between nurses and social workers. In some instance, role conflict has resulted in FCGs not getting the support that is needed. Many participants acknowledged that the nursing-social work team works well if the roles are blended. Such a blending works well to meet the needs of FCGs as they appear more receptive to social work assistance once it is introduced and supported by the nurse. In instances where social work service is not available or inadequate, however, education to assist home care nurses to feel comfortable in working with psychosocial issues may be warranted.

**Assessing the Needs of Family Caregivers**

In order to prevent negative health outcomes, an assessment of FCG needs is required. While in theory FCGs are an important component of the unit of care in palliative care, in practice, many FCGs say that their needs are not considered to the extent that they likely should be; they are important proxies for reporting patient related issues, but as people with legitimate needs of their own, they are often not given the same consideration as the person who is dying.

Providers asked if we might suggest an assessment tool that would be useful in identifying those FCGs at risk for negative health outcomes. In this study we identified a number of indicators for those most at risk (see page 12) that could be used as “red flags” to indicate those FCGs who might be in need of assistance. At the same time, assessing traits such as resilience, optimism and stress can be a timely process that in practice, may not be realistic to complete given clinician time constraints. The development of a quick, practical FCG assessment tool that was sensitive to identifying FCGs who may be susceptible to negative health outcomes

would be useful in practice and having such a tool validated through research would provide reliable, valid assessment information.

### Health Care System Improvements

While our study did not explicitly address health care system improvements, many FCGs had advice about the kinds of things that would be helpful to them in coping with the demands of caregiving. For example, having access to specialized palliative care services 24 hours a day, 7 days a week was a recommendation that came forward often. While 24 hour access to a call centre, such as the BC Nurse Line was seen as helpful, FCGs said that speaking with someone who knew something about their case and about palliative care was most helpful to them. Most importantly, FCGs felt reassured when they believed the health care system would be there to support them if they needed it.

The delivery of home support was an issue that arose in almost every interview with FCGs and in our discussion groups. The home support system, to a large degree, is simply not working well to meet the needs of families in palliative care. Inconsistent care workers, their varying degrees of educational preparation and the absence of night service were issues repeatedly mentioned that need to be resolved. Family caregivers and providers claim that resolution of these issues would bring about the most significant improvements to the care system.

Family caregivers are better able to manage the demands of caregiving when the dying person is well taken care of. Management of pain and other distressing symptoms is of primary importance to FCGs and continued efforts to improve the delivery of palliative care to prevent unnecessary suffering should be a goal of any health care system. Education for providers and resources to support effective support for patients and families will do much to enhance the quality of life of FCGs. The fact that dissatisfaction with the quality of health care received was an important factor associated with reduced quality of life and increased depression among FCGs points to a need to further explore system issues that are in need of improvement to enhance care for dying people and their family members.

## Conclusion

Family caregiving is an important issue in Canadian Society. Family members do and will continue to provide the vast majority to people in the palliative phase. Family caregivers are not only a key player within the health care system, they are necessary to keep our system going. The findings and recommendations contained in this report serve as a reminder that caring for a dying person can be a rewarding experience, but that is not without sacrifice and potential repercussions. The societal costs of ignoring such issues, both in human and monetary terms, are extremely high. However, the study findings and subsequent recommendations demonstrate that remedies are available. The findings and recommendations contained in this report provide some direction to begin focusing on the needs of the family caregiver at the same time as focusing on the needs of the dying person.

## *Appendix A: Questionnaires Used in Quantitative Survey*

Questionnaire	Purpose	Reference
Caregiving Assistance Scale (CAS)	To measure the extent of care needed by the Care Receiver (CR).	Cameron, J.I., Franche, R.L., Cheung, A.M., & Stewart, D.E. (2002). Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. <i>Cancer</i> , 94, 521-527.
McGill Quality of Life Questionnaire – Family Caregiver Version (MQoLQ-FCV)	To measure the quality of life, including the existence of psychological symptoms, physical symptoms, physical well-being, existential well-being, and support	Cohen, R., Leis, A.M., Kuhl, D., Carboneau, C., Ritvo, P., & Ashbury, F.D. (2006). QOLLI-F: measuring family carer quality of life. <i>Palliative Medicine</i> , 20,755-767.
Centre of Epidemiology Studies – Depression Scale (CES-D)	Designed for use in the general population to indicate depressive symptomology.	Radloff, L.S. (1977). The CES-D scale: A self-report depression scale for research in the general population. <i>Applied Psychological Measurement</i> , 1(3), 385-401.
Caregiver Reaction Assessment (CRA)	To measure burden and conflict with others. Comprised of caregiving consequences (physical, psychological, emotional, social, and financial), stress effects, tasks, and restrictions that cause discomfort for the caregiver.	Given, C.W., Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (1992). The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. <i>Research in Nursing &amp; Health</i> , 15, 271-283.
Southern California Longitudinal Study of Three-generation Families measures of positive affect	Pertains to the quality of the relationship between the FCG and CR.	Mangen, D.J., Bengtson, V.L., & Landry, P.H. (Eds.). (1988). <i>Measurement of intergenerational relations</i> . Beverly Hills, CA: Sage.
Caregiver Impact Scale (CIS)	Measures lifestyle interference or interference with other roles. It is the extent to which CRs illness or treatment interferes with the FCGs ability to participate in a variety of valued activities.	Cameron, J.I., Frache, R.L., Cheung, A.M., & Stewart, D.E. (2002). Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. <i>Cancer</i> , 94, 521-527.
Ways of Coping Scale- Short Version (WoC)	To measure the strategy used to manage the internal and external demands of stressful situations.	Folkman, S., Lazarus, R.S., Pimley, S., & Novacek, J. (1987). Age differences in stress and coping processes. <i>Psychology and Aging</i> , 2, 171-184.



..... *Family Caregiver Coping in End-of-Life Cancer Care*

Queen's Quality Care Survey (QoC)	To measure the FCGs satisfaction with health care received by the patient and family.	Heyland, D.K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D., Shortt, S., Tranmer, J., Lazar, N., Kutsogiannis, J., & Lam, M. (2006). What matters most in the end-of-life care: perceptions of seriously ill patients and their family members. <i>Canadian Medical Association Journal</i> , 174(5), DOI:10.1503/cmaj.050626.
Family Caregiving Inventory	To measure how prepared the FCG felt for the demands of caregiving.	Archbold, P.G., Stewart, B.J., Greenlick, M.R., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. <i>Research in Nursing &amp; Health</i> , 13, 375-384.
Life Orientation Test-Revised (LOT-R)	To measure the level of optimism of the FCG.	Scheier, M.F., Carver, C.S., & Bridges, M.W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): A re-evaluation of the life orientation test. <i>Journal of Personality and Social Psychology</i> , 67(6), 1063-1078.
Perceived Stress Scale (PSS)	To measure the degree of stress felt by the FCG	Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. <i>Journal of Health and Social Behavior</i> , 24(4), 385-396.
Resilience Scale	To measure resilience or "emotional stamina and adaptability" under challenging experiences.	Wagnild, G.M. & Young, H.M. (1993). Development and psychometric evaluation of the resilience scale. <i>Journal of Nursing Measurement</i> , 1(2), 165-178.
Family Relationship Index (FRI)	To measure family relationship environment.	From the Family Environment Scale (FES) Moos, R.H., Moos, B.S. (1981). <i>Family environment scale manual</i> . Palo Alto, CA: Consulting Psychologist Press.
Brief Assessment of Sense of Coherence (BASOC)	To measure how connected the FCG felt to their community.	Schumann, A., Hapke, U., Meyer, C., Rumpf, H., & John, U. (2003). Measuring sense of coherence with only three items: A useful tool for population surveys. <i>British Journal of Health Psychology</i> , 8, 409-421.



..... *Family Caregiver Coping in End-of-Life Cancer Care*

<p>Memorial Symptom Assessment Scale – Short Form (MSAS-SF)</p>	<p>To measure the frequency and extent of symptoms felt by the CR as observed by the FCG.</p>	<p>Chang, V.T., Hwang, S.S., Reuerman, M., Kasimis, B.S., &amp; Thaler, H.T. (2000). The memorial symptom assessment scale short form (MSAS-SF). <i>Cancer</i>, 89, 1162-1171.</p>
<p>Medical Outcomes Study – 12-Item Short-form Health Survey (SF-12)</p>	<p>To measure the emotional and physical health of the FCG.</p>	<p>Ware, J.E., Kosinski, M., Turner-Bowker, D.M., &amp; Gandek, B. (1996). How to Score Version 2 of the SF-12® Health Survey. Lincoln, Rhode Island; QualityMetric Incorporated.</p>

## *Appendix B: Phase 1 Demographics*

Age: N = 64; Mean = 62; Range = 33 - 87 Gender: N = 65; Female = 51; Male = 14		
Variable	Number	% (Rounded)
Education N = 65		
High school or less	28	43
Greater than high school	37	57
Ethnicity N = 65		
Caucasian	65	100
Other	0	0
FCG Living Arrangements N = 64		
Yes, lives with patient	49	77
No, lives in separate dwelling	15	23
Employment N = 65		
Working (full-time, part-time, or self employed)	22	34
Retired	37	57
Other (paid/unpaid leave, not employed)	6	9
FCG Relationship with Patient N = 65		
Spouse	43	66
Parental	12	19
Other (friend or other family member)	10	15
Patient Primary type of Cancer N = 65		
Lung	11	17
Gastrointestinal	12	19
Prostate	7	11
Breast and female sex organs	9	14
Brain	9	14
Other	17	25
Bereaved N = 65		
Yes	36	55
No	29	45
Number of Hours Caregiving per Week N = 29		
less than 10	1	3
11-20 hours	3	10
21-40 hours	4	14
41-60 hours	5	17
61-150 hours	7	24
24/7	9	31

## *Appendix C: Phase 2 Demographics*

Age: N = 317; Mean = 58; Range = 23 - 93 Gender: N = 317; Female = 220; Male = 97		
Variable	Number	% Rounded
<b>FCG Education N=317</b>		
High school or less	100	32
Greater than high school	217	68
<b>FCG Ethnicity N=317</b>		
Caucasian	264	83
Other	53	17
<b>FCG Marital Status N=317</b>		
Married or living as	256	81
Not married	61	19
<b>FCG Living arrangements N=312</b>		
Yes, lives with patient	237	75
No, lives in a separate dwelling	75	24
<b>FCG Employment N=317</b>		
Working (full-time, part-time, or self employed)	111	35
Retired	130	41
Other (paid/unpaid leave, not employed)	76	24
<b>FCG Relationship with patient N=317</b>		
Spouse	164	52
Parental	117	37
Other (friend, other family member)	36	11
<b>FCG Religious/spiritual beliefs N=316</b>		
No religion	100	32
Religion stated	216	68
<b>Patient Gender N=317</b>		
Male	135	43
Female	182	57
<b>Primary type of Cancer of the Patient N=317</b>		
Lung	70	22
Breast and female sex organs	54	17
Gastrointestinal	51	16
Prostate	25	8
Renal	18	6
Lymphoma	17	5
Brain	13	2
Other	69	22
<b>Community Characteristics N=317</b>		
Population:		
100,000-999,999	256	80
30,000-99,999	32	10
10,000-29,999	25	8
1000-9999	4	1
<b>Bereaved N=317</b>		
Yes	53	17
No	264	83

..... *Family Caregiver Coping in End-of-Life Cancer Care*

Hours per Week Providing Care N=316		
10-20	43	14
21-30	47	15
31-40	30	10
41-50	28	9
51-60	7	2
61-70	13	4
71-80	8	3
>80	140	44
Someone Unpaid who Assists N=316		
Yes	214	68
No	102	32
Anyone else FCG provides help to N=316		
Yes	77	24
No	239	80
Besides cancer, does the patient have any other health problems? N=317		
Yes	204	65
No	113	36

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