

Family Caregiver Coping in End-of-Life Cancer Care

Final Report
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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.

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

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:

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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

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

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 cope¹. Many family caregivers neglect their own physical and mental health, focusing only on the needs of the dying person^{2,3}. 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^{4,5,6,7,8}.

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 experience⁹. 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.9(wa)-3.7(rd o3893 -1te)-4raishtrengthslity

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 FCGsⁱ;
- 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 FCGsⁱⁱ

Data Analysis

An interpretive thematic analysis¹⁰ 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 types.

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- (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 "appro

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.

The patients’ outlook on the illness also influenced caregivers’ ability to cope. Many caregivers commented that coping with caregiving was mu

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.

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

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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.



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 impo

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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^{11 12 13}.

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.

<i>Reduced quality of life was associated with:</i>	<i>Greater depressive symptoms were associated with:</i>
Increased feelings of burden	Lower income
Increased amount of role interference	Increased amount of role interference
Increased levels of FCG stress	Decreased levels of sense of coherence
Decreased levels of sense of coherence	Increased feeling of burden
Increased depressive symptoms of the FCG	Decreased levels of FCG resilience
Dissatisfaction with the quality of health care received	Decreased levels of FCG optimism
Increased number of patient symptoms	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	

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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
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RECOMMENDATIONS

These recommendations arise from the research te

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

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). QOLLTI-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 & 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.

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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 & 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.

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

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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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