

# Developing a Living with Hope Program for Caregivers of Family Members with Advanced Cancer

WENDY DUGGLEBY and KAREN WRIGHT, College of Nursing, University of Saskatchewan, Saskatoon, Saskatchewan, ALLISON WILLIAMS, School of Geography and Geology, McMaster University, Hamilton, Ontario, LESLEY DEGNER, Faculty of Nursing, Evidence-Based Nursing Practice, Helen Glass Centre for Nursing, University of Manitoba, Winnipeg, Manitoba, ALLISON CAMMER, Institute of Agricultural Rural and Environmental Health, Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan, Saskatoon, Saskatchewan, LORRAINE HOLTSLANDER, College of Nursing University of Saskatchewan, Saskatoon, Saskatchewan, Canada

**Abstract** / A theory-based intervention, the Living with Hope Program (LWHP), was designed to foster hope in caregivers of family members with advanced cancer. The LWHP was developed from qualitative data and using Harding and Higginson's recommendations for family caregiver interventions as a guide. The LWHP is: a) focused specifically on the caregivers themselves, b) theory based, c) feasible, d) acceptable, and e) pilot tested. The program consists of a hope video and a hope activity titled Stories of the Present. A mixed-method, concurrent triangulation, pre- and post-test design was used to pilot test the LWHP. The results of the pilot test suggest the LWHP is easy to use, flexible, and feasible, and shows promise in increasing hope and quality of life scores in family caregivers.

**Résumé** / Le Programme Vivre d'Espoir (Living with Hope Program), un programme d'intervention basé sur une théorie de l'espoir, a été conçu pour favoriser l'espoir chez les soignants s'occupant des membres de leur famille atteints du cancer. Ce programme a été développé à partir de données qualitatives et en ayant comme guide les recommandations de Harding and Higginson sur la façon d'intervenir auprès des soignants familiaux. Vivre d'Espoir est : a) principalement centré sur les soignants, b) fondé sur une théorie, c) faisable, d) raisonnable, et e) mis à l'essai dans un projet pilote. Le programme consiste en un vidéo sur l'espoir et la tenue d'un journal personnel. Le projet pilote a utilisé la méthode mixte, la triangulation simultanée et le modèle pré- et post-tests pour faire l'évaluation du programme. Les résultats indiquent que cette forme d'intervention est facile à utiliser, flexible et faisable et porteuse de promesses pour augmenter l'espoir et la qualité de vie de ces soignants.

## INTRODUCTION

It is not only the cancer patient who experiences the crisis and distress associated with cancer; the family member does as well (1,2). The stress of caring for dying persons at the end of life has been well documented (3–5). However, there is very little research in the area of interventions to support caregivers of family members with advanced cancer (6–8). A psychosocial supportive

hope-focused intervention may benefit family caregivers. Hope is a psychosocial and spiritual resource used by caregivers of family members with advanced cancer to manage and deal with the caregiver experience (9–11).

Research studies have suggested that hope can be fostered by cognitive reframing interventions in healthy older adults (12), veterans (13), newly diagnosed cancer patients (14), adults with recurrent cancer (15), and older palliative cancer patients (16). These cognitive reframing interventions, or hope-intervention programs, involved a series of cognitive activities that assisted individuals in maintaining and enhancing hope and, in three studies, increased quality of life for the subjects (14–16).

Hope has been described in four qualitative studies of caregivers of family members with advanced cancer as important in helping them deal with the caregiving experience (9–11,17). In these studies, hope was defined as a dynamic process that included faith, relationships, and need for connection, as well as goal setting and cognitive reframing. Their hope differed from that of other populations as the objects of their hopes were to continue caregiving and for the comfort of their terminally ill family member. In a study comparing the hope of caregivers and of the terminally ill family member, levels of hope were found to be significantly lower for the caregivers than the family member with terminal illness (18). These findings suggest that fostering hope in caregivers of family members with advanced cancer is important. No reported studies have evaluated a hope intervention to foster hope in family caregivers. This article describes the development of a theory-based intervention, the Living with Hope Program, (LWHP) for caregivers of family members with advanced cancer, and the results of a pilot test evaluating its acceptability, ease of use, and flexibility.

## THEORETICAL FRAMEWORK: HANGING ON TO HOPE

Theories and conceptual models of hope have tried to capture the complex, dynamic nature of hope (19–25). These theories, however, were developed using noncaregiver populations and, thus, do not appear to be representative of this population. As well, they do not appear to be congruent with the findings from descriptive studies exploring the hope experience of caregivers of family members with advanced cancer.

One new emerging theory of hope, Hanging on to Hope, was developed from a grounded study of hope in caregivers of terminally ill family members by the research team. It was the foundation for the development of the Living with Hope Program (LWHP) (Figure 1) (16). The processes of hope for caregivers were identified as being: living in the moment, being positive, and writing their own story. Hope was for the future, but their future was defined in the moment. Spirituality and positive relationships facilitated this process. These processes fostered hope and, in so doing, positively influenced their quality of life.

### Developing the Living with Hope Program

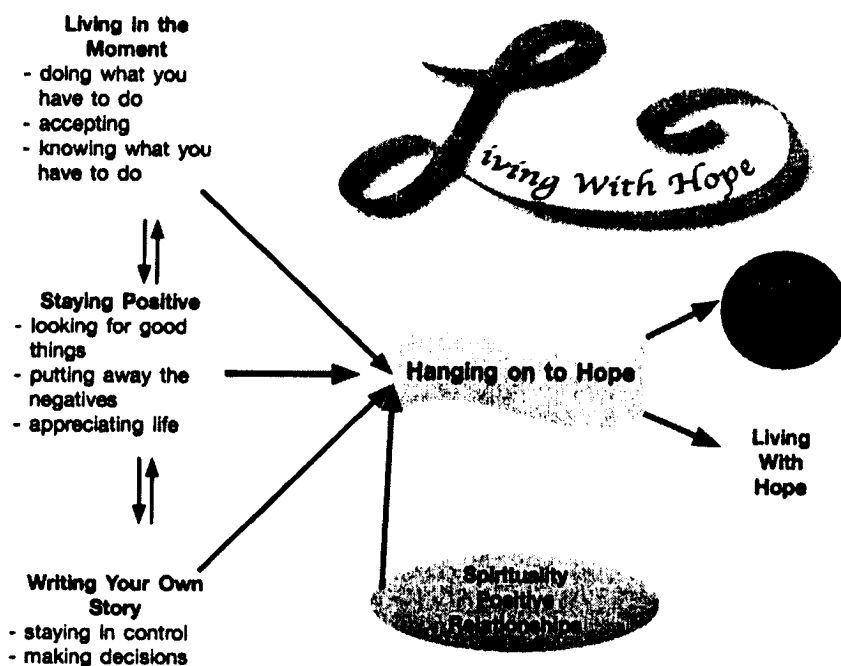
Recommendations by Harding and Higginson (7) for family caregiver interventions were used

as a guide to develop the LWHP. Following an extensive review of family caregiver research, Harding and Higginson suggested that interventions for caregivers of terminally ill family members should be: focused specifically on the caregivers themselves, theory-based, feasible, acceptable, and pilot tested. In keeping with these suggestions, the LWHP is theory-based; focuses on the caregivers themselves, their challenges and hopes; and has been pilot tested. The LWHP consists of Stories of the Present and the viewing a 17-minute video titled *Living with Hope*. Stories of the Present is a hope-focused activity in which family caregivers write in a journal for approximately five minutes near the end of each day, reflecting on their caregiver challenges and what gave them hope that day (Figure 2).

### Caregiver-Focused and Theory-Based

The critical inputs for the LWHP incorporated three subprocesses of the Hanging on to Hope theory (Figure 1): living in the moment, having a positive approach, and writing their own story. Critical inputs address the nature of the intervention in terms of what is necessary to produce the expected effects (26). The Stories of the Present journal writings in the LWHP reflect what is happening to the caregivers now (living in the moment), an opportunity to write their own story, and what gave them hope (a

Figure 1 / HANGING ON TO HOPE (adapted from Holtzlander et al., 2005)



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**Figure 2 / INSTRUCTIONS FOR STORIES OF THE PRESENT**


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Take 5 minutes near the end of the day to reflect.  
 Everyday, write in this binder; try to focus on:  
 reflections,  
 challenges,  
 what gave you hope today.  
 Remember to focus on your experiences.  
 This is about you right now.  
 Write about your day in any way you'd like; use point form if you'd like.  
 Don't worry about grammar or spelling.

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positive approach). The benefits of keeping a journal include helping individuals cognitively organize stressful events (27). The instructions for the Stories of the Present journal writing facilitate the cognitive organizing of the caregivers' challenges, including a cognitive reframing of what gave them hope.

Another aspect of the LWHP is the viewing of an international award-winning video developed by the research team based on qualitative hope research. One of the strongest benefits of videotaped presentations is video modeling, which occurs when viewers identify with the individuals on the videotape and perceive themselves as capable of performing specific tasks (28,29). Video modeling has been used to foster hope with a hope-focused activity in terminally ill cancer patients (16). In order to achieve video modeling, actual caregivers of terminally ill family members were videotaped describing their hope, and how they foster and maintain it.

### Feasibility and Acceptability

Interventions must be flexible and easy to use in order to be feasible or easily possible. The caregiving experience is one of uncertainty (30,31) and it is often difficult for caregivers to plan activities or leave the person they are caring for alone (32). The Stories of the Present can be written in a journal at any time near the end of the day. The caregivers are provided with journals that are portable and can be completed anywhere. They are also asked to take five minutes for this hope activity, but what they write and how long they spend on the activity is up to the individual. They are asked to keep a journal for two weeks, considered the optimum length of time for this activity (33). As the LWHP is brief, it also makes it more acceptable to caregivers because of their time demands. The LWHP is also feasible because it is self-administered. A self-administered intervention is more cost-effective than a one-on-one intervention, and can be more readily integrated into health services delivery (7).

## PILOT STUDY

The purpose of the pilot study was to evaluate the LWHP for ease of use, feasibility, acceptability, and potential influence on increasing hope and quality of life for caregivers of family members with advanced cancer. The specific aims of the pilot study were to: a) evaluate the study procedures (recruitment and data collection protocols) to determine if they are realistic and workable; b) evaluate LWHP for ease of use, acceptability, and feasibility; and c) collect preliminary data to determine feasibility and potential effectiveness of LWHP in increasing hope and quality of life scores for family caregivers. This study received ethical approval from a university ethics review board.

### Design

The pilot study used a mixed method, concurrent triangulation (34), pre- and post-test design. Quantitative and qualitative data were collected at the same time from all subjects. Baseline data were collected, followed by data post-treatment at one (visit two) and two weeks (visit three) after the first visit. At visits two and three, qualitative open-ended questions were used to evaluate the LWHP and study procedures (Figure 4).

### Sample and Setting

The pilot was conducted in the homes of family caregivers caring for palliative patients receiving services from a rural Canadian palliative home care program. Inclusion criteria were: a) men or women, b) English speaking, c) 18 years of age or older, and d) residing with and providing continuous care to a terminally ill family member with cancer who was receiving services from the palliative home care program.

Using convenience sampling, 10 family caregivers completed the study. The sample size of 10 was chosen based on Birkett and Day's recommendations for pilot sample sizes (35). All who were approached agreed to participate. Eight of the participants completed data collection for all three-time periods. One completed only the first visit because of another death in the family, and one participant did not complete the third visit due to deterioration of the terminally ill family member's condition.

### Measures

The data were collected using four different tools, three of which were quantitative and one qualitative.

*a) Demographic Form.* Information such as age, gender, relationship to patient, occupation

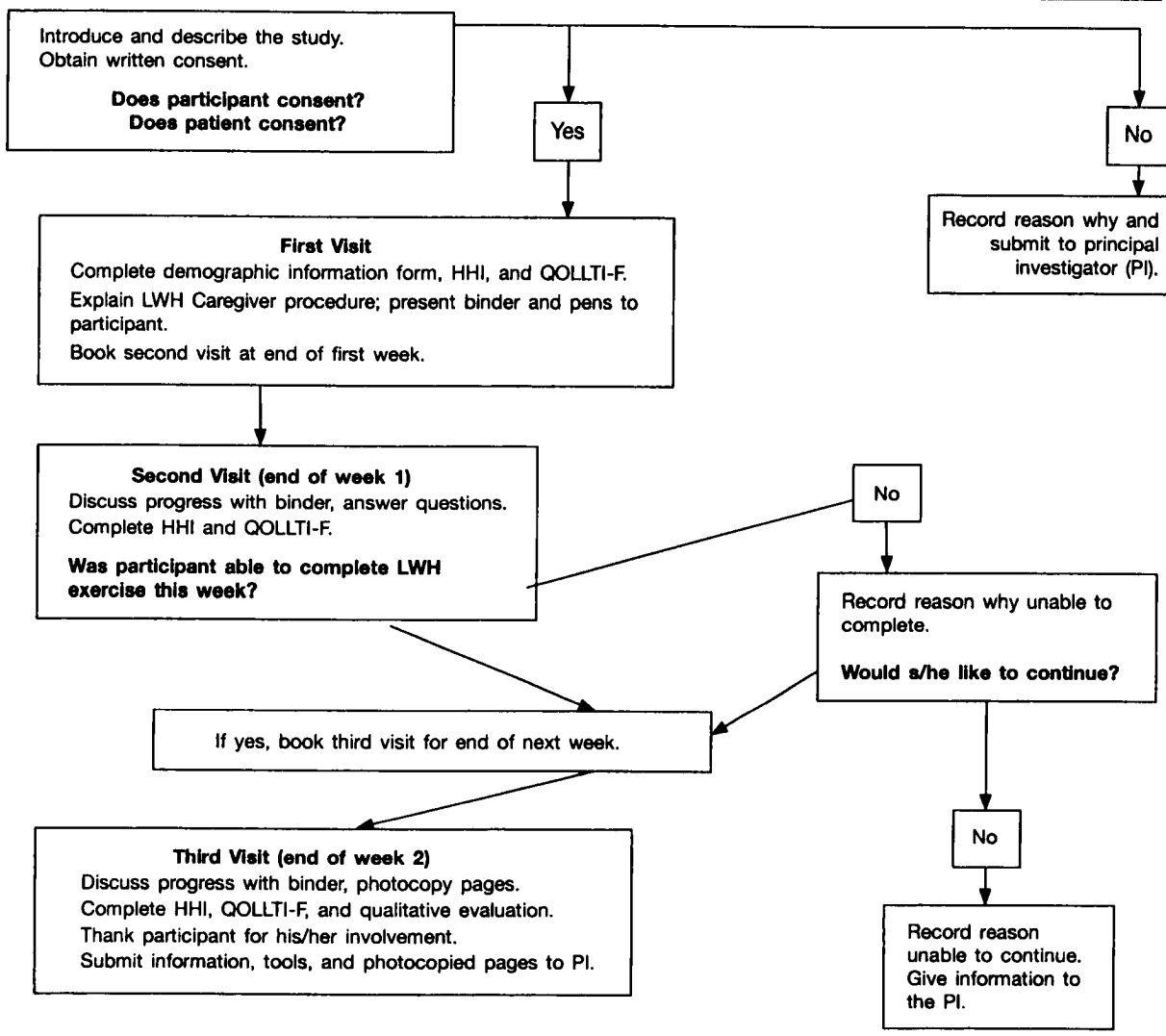
(current or past), ethnicity, income, religious affiliation, any medical conditions, and education levels were collected. Family member's information was also collected, including age, sex, and diagnosis.

**b) Herth Hope Index (HHI).** The Herth Hope Index is a 12-item (1-4 point) Likert scale that delineates three factors of hope: temporality and future; positive readiness and expectancy; and interconnectedness (36). The HHI has been found to take approximately five minutes to complete. Summative scores range from 12-48, with a higher score denoting greater hope. The HHI has been found to be reliable (test-retest  $r=0.91$ ,  $p<0.05$ ) and valid (concurrent validity  $r=0.84$ ,  $p<0.05$ ; criterion  $r=0.92$ ,  $p<0.05$ ; divergent  $r=-0.73$ ,  $p<0.05$ ) (36). The HHI has been used successfully in studies with terminally ill patients (36) and family caregivers (10,11).

**Figure 3 / OPEN-ENDED EVALUATION INTERVIEW QUESTIONS**

- What was it like to be part of this study?
- Was there anything that helped you to participate?
- Was there anything that hindered your participation?
- What did you like best about the hope activities (including the video)?
- What did you like least?
- Were there parts of the activities that were helpful or not helpful?  
(prompt) What were they?  
(prompt) Why were they helpful or not?
- Were there easy or difficult parts of the study?
- Did you find the hope and quality-of-life questions easy or difficult to complete?
- How can the hope activities be improved?
- Did working on the activities change your hope?  
(prompt) Increase or decrease?  
(prompt) Why did you think it changed/didn't change your hope?

**Figure 4 / DATA COLLECTION PLAN FOR LWH- CAREGIVER**



c) *Quality of Life in Life Threatening Illness-Family Caregiver (QOLLI-F)*. The QOLLI-F is a 16 item (0–10) Likert scale comprised of seven subscales representing the domains important to the quality of life of caregivers of terminally ill family members (37). The subscales are environment, patient state, own state, outlook, quality of care, relationships, and financial worries. The higher the total score, the higher the quality of life. This scale takes approximately 10 minutes to complete, and has established reliability ( $\alpha=0.77-0.80$ ) and validity ( $p<0.001$ ) (37).

d) *Qualitative Open-ended Evaluation Questions*. Open-ended face-to-face audio-taped interviews were conducted to evaluate the study protocols and LWHP. The interview guide is described in Figure 3.

### Data Collection

The data collection procedure is illustrated in Figure 4. Using the selection criteria, the palliative care program coordinator identified potential participants and asked if they would like to speak to a researcher about possibly participating in a study. If they agreed the palliative care program coordinator contacted the trained research assistant (RA). The RA, who was a registered nurse, contacted the potential subjects by phone and arranged to meet with them in their homes, at a time convenient for them, in order to explain the study. At the first visit, a written informed consent was obtained from the subjects and permission from the terminally ill family member was granted. The subjects first completed the demographic form, the HHI, and QOLLI-F before viewing the *Living with Hope* video. Following viewing of the video, the RA asked the subjects to take five minutes at the end of each day over the next two weeks to write about their thoughts, challenges, and what gave them hope. One week later, the RA visited the subjects and asked them to complete the HHI and QOLLI-F, and made a photocopy of their journal entries. The RA then returned one week later to have the subjects complete the HHI and QOLLI-F, and to evaluate the LWHP and study protocols using open-ended questions.

### Data Analysis

Audio-taped interviews were transcribed verbatim by a transcriptionist and checked by the RA for accuracy. Qualitative data was managed using the Nonnumerical Unstructured Data Indexing, Searching and Theorizing (NUD\*IST) software. The interview data was analyzed using Patton's thematic analysis methodology (38). Using this methodology, patterns of main points and topics were identified. From the main points and top-

ics, themes emerged. Quantitative data were cleaned, checked, and entered into SPSS. Descriptive statistics were used to analyze recruitment and retention data, demographic data, and HHI and QOLLI-F-scores.

## PILOT RESULTS

### Sample

The demographic characteristics of the study participants are presented in Table 1. The majority of the caregivers were older (mean age: 60.3 years), female, Caucasian, well-educated, and had a range of incomes. They generally reported no medical conditions and good health status. They

**Table 1 / INFORMAL CAREGIVERS DEMOGRAPHICS (n=10)**

	Mean	Frequencies
Age (years)	60.3 (SD 15.46; range: 38–87)	
Years of education	13.5 (SD 2.014; range:10–16)	
Gender		6 female 4 male
Marital status		9 married 1 widowed
Relationship to patient		4 husband 3 wife 2 daughter 1 daughter-in-law
Ethnicity		10 Caucasian
Religious preference		5 Protestant 4 Catholic 1 other
Occupation		4 professional 4 labourer 2 other
Current income		1 less than \$10,000 1 \$10,000–\$19,999 4 \$20,000–\$29,999 2 \$40,000–\$49,999 1 \$50,000–\$59,999
Medical conditions		7 none 2 diabetes 1 heart condition
Any help with caregiver		4 yes (family and home care) 6 no
Length of time caregiving (months)	9 (SD.15.167; range: 1–41)	
Length of time palliative (months)	4.03 (SD 3.335; range: 1–13)	
Using other services		9 no 1 yes
Health status	2.9 (SD 0.738; range:1–4)	1 much better than a year ago 8 the same 1 much worse than a year ago
Gender of terminally ill family member		5 male 5 female
Age of terminally ill family member (years)	69.4 (SD 16.440; range: 45–89)	

were caring for and living with a terminally ill family member in their home. The majority of the persons they were caring for were older (mean age: 69.4 years), all had a diagnosis of cancer, and all were receiving palliative home care services.

### Study Procedures

The first aim of the pilot study was to evaluate study procedures (recruitment and data collection) to determine if they were realistic and workable. Recruitment rates were high, as all who were approached agreed to participate. Only two subjects did not complete the study. The overall evaluations of study procedures by the participants were positive. Except for the two participants who did not participate in all three visits, there were no missing data. One comment from a study participant regarding the HHI and QOLLI-F was that they found it difficult to choose a score on the hope and quality of life questionnaires as the scores didn't represent the complexity of feelings they were experiencing; they preferred the open-ended questions.

Participants said factors that limited their participation were time, energy, fatigue, and deteriorating condition of the person they were caring for. Factors that enhanced participation were contact with the RA, flexibility, ease of activities, sharing their experiences with others, experiencing a benefit from participation, and feeling like this research would help others.

### Living With Hope Program

The second aim of the pilot study was to evaluate LWHP for acceptability and feasibility. The participants described the LWHP video as introducing the idea that there are many ways to foster hope and that hope is not focused on cure. None of the participants viewed the video again, although a copy was left in their homes.

Study participants completed 101 journal entries over the two-week period. On average, the participants completed 5.5 journal entries per week. While this is less than one per day, the participants spent an average of 9.28 minutes per journal entry, which exceeds the five minutes requested. The qualitative data was very positive in evaluation of the LWHP. It was described as easy, short, and simple to do. One participant said, "Oh, it was fairly simple to do. Like I mean, it wasn't a big deal." Others said it was difficult to begin journal writing, but it became easier with time. Another said: "The journaling itself was very helpful, but in order to do it, I needed someone to tell me I had to do it, you know." One participant did not enjoy writing in the journal as it brought up bad emotions and they

did not want to reflect badly about their dying loved one. Suggestions made by the study participants to improve the LWHP included: to write in the journal throughout the day, whenever there was time, instead of at the end; to audio-record journal entries instead of writing; and to have the opportunity to share their journals with others.

### Preliminary Data for Hope and Quality of Life

The third aim of the pilot was to collect preliminary data to determine the feasibility and potential effectiveness of LWHP in increasing hope and quality-of-life scores. Table 2 presents the hope and quality-of-life scores for the study participants. Although the sample size precluded using statistical tests to determine differences between the means, the mean scores did increase over the duration of the program.

Qualitative data from participants suggests that participating in the project had an influence on their hope. Themes identified were: finding hope in different ways; looking for positives; focusing on hope; and the benefits of concentrating on themselves or of having their feelings valued/heard. See Table 3 for examples

**Table 2 / MEAN HHI AND QOLLI-F SCORES (n=10)**

	Baseline (pre)	Visit 2 (one week post)	Visit 3 (two weeks post)
HHI	37 (SD 4.269; range: 29-43)	38.22 (SD 3.346; range: 33-44)	39.63 (SD 2.973; range: 34-43)
QOLLI-F	6.87 (SD 1.18; range: 4.53-8.60)	7.44 (SD 1.52; range: 5.73-10)	8.14 (SD 1.13; range: 6.74-9.41)

**Table 3 / THEMES AND DATA EXAMPLES FROM THE QUESTION: DID WORKING ON THE ACTIVITIES CHANGE YOUR HOPE?**

Themes	Data Examples
Finding hope in different ways	"So in a sense the journal helped me to look for hope and to see it in different ways other than...because there is no hope for recovery."
Looking for positives	"Thinking about the positive things—one of the gifts to myself." "And the journaling, I found it was good for me to take stock at the end of the day. I had to look for some good things that happened."
Focusing on hope	"Hope is not just a big picture. You can hope for little things too...the small things. And you can take hope or positive, get positive feelings and focus on the immediate."
The benefit of concentrating on themselves, or having their feelings valued/heard	"Before actually you came and we did this I was depressed. This...kind of enabled me to think about me and my day in relation to Dad." "...the journaling felt like I was sharing my thoughts with someone because I knew someone was going to read it and that was important." "...but to have someone read it...it kind of shares the journey with you."

of qualitative data. Only one participant felt the process did not help and that the experience did not affect their hope. None of the participants suggested that the LWHP had a negative effect and all enjoyed participating in the study.

### Limitations

There are several limitations to this pilot study related to subjects and design. Sample size was small, although sufficient for a pilot study (35). The pilot study participants were homogeneous in nature; results may differ with varying religious and ethnic participant backgrounds. The wide age range may also have had an influence on the pilot study results, as well as the length of caregiving and the relationship of the caregiver to the terminally ill family member. The pilot study used a pre- and post- design because the purpose of the pilot was to determine the ease of use and feasibility of the LWHP. More advanced testing of the LWHP should be longitudinal and include comparison groups to determine the effectiveness of the LWHP in increasing hope and quality-of-life scores.

### DISCUSSION

The pilot study results suggest that the study protocols were easy to use, and that the LWHP is feasible and acceptable to caregivers. Using qualitative, open-ended questions to evaluate both the study procedures and the LWHP was beneficial; several suggestions for improvements were made, including to continue using a mixed-method approach. Quantitative measures may only explain one aspect of a complex phenomenon, whereas a combination of quantitative and qualitative information contribute to a more comprehensive understanding of study outcomes (34).

Missing data is a potential issue in any clinical research study and the results of this study suggest that missing data may be an issue with caregiver research as well. Studies in palliative care often have high attrition rates (39). This should be considered in the design of a larger study in terms of sample size and including statistical ways of handling missing data. Subject recruitment for a larger study will need to include palliative home care programs with larger populations. As well, continuing to keep the study burden as low as possible may facilitate recruitment and retention of subjects (40).

### CONCLUSION

Suggestions from the study regarding the LWHP will increase its flexibility by adding choices of

audio recording and also computer use for keeping journals. The variability in days of journal writing raises the issue of dosage. It is unknown if the effectiveness of the intervention is related to the number of times journal entries are made or to the process. The theory Hanging on to Hope (9) suggests that hope is a process, so that the number of times may not be relevant. This needs to be further evaluated in a larger study.

The process used to develop the LWHP from qualitative data and using the criteria outlined by Harding and Higginson for caregiver interventions (7) may have resulted in a promising intervention. The LWHP is flexible and acceptable to caregivers of terminally ill family members, and may positively influence hope and quality of life. Piloting the intervention using a mixed-method approach has also provided important information for the further refinement of the LWHP and study design. Further refinement and testing of the LWHP has the potential to result in a much needed intervention program to foster hope in caregivers of terminally ill family members.

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*Date received, June 14, 2006; date accepted, December 8, 2006.*

### ACKNOWLEDGEMENTS

This study was funded by Canadian Institutes of Health Research. We want to thank the palliative care patients, families, and staff from the Five Hills Health Region for their assistance in facilitating this study.

### REFERENCES

1. Lewis F. The impact of cancer on the family: a critical analysis of the research literature. *Patient Educ Couns* 1986; 10: 269-289.
2. Given B, Wyatt G, Given C, Sherwood P, Gift A, DeVoss D, Rahbar M. Burden and depression among caregivers of patients with cancer at the end of life. *Oncol Nurs Forum* 2004; 31(6): 1105-1117.
3. Schachter S. Quality of life for families in the management of home care patients with advanced cancer. *J Palliat Care* 1992; 8(3): 61-66.
4. Stajduhar K, Davis R. Death at home: challenges for families and directions for the future. *J Palliat Care* 1998; 14(3): 8-14.
5. Brazil K, Bedard M, Willison K, Hode M. Caregiving and its impact on families of the terminally ill. *Aging Ment Health* 2003; 7(5): 376-382.
6. Hudson P, Aranda S, Kristjanson L. Meeting the supportive needs of family caregivers in palliative care: challenges for health professionals. *J Palliat Med* 2004; 7(1): 19-25.
7. Harding R, Higginson IJ. What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliat Med* 2003; 17: 63-74.
8. Hudson P. A critical review of supportive interventions for family caregivers of palliative stage cancer patients. *J Psychosoc Oncol* 2004; 22(4): 77-92.

9. Holtslander L, Duggleby W, Williams A, Wright K. The experience of hope for informal caregivers of palliative patients. *J Palliat Care* 2005; 21(4): 285-291.
10. Herth K. Hope in the family caregiver of terminally ill people. *J Adv Nurs* 1993; 18: 538-548.
11. Borneman T, Stahl C, Ferrell B, Smith D. The concept of hope in family caregivers of patients at home. *J Hosp Palliat Nurs* 2002; 4(1): 21-33.
12. Staats S. Quality of life and affect in older person. Hope, time frames, and training effects. *Curr Psychol Res Rev* 1991; 10: 21-30.
13. Tollett J, Thomas S. A theory-based intervention to instill hope in homeless veterans. *ANS Adv Nurs Sci* 1995; 18(2): 76-90.
14. Rustoen T, Wiklund I, Hanestad B, Moum T. Nursing intervention to increase hope and quality of life in newly diagnosed cancer patients. *Cancer Nurs* 1998; 21(4): 235-245.
15. Herth K. Enhancing hope in people with a first recurrence of cancer. *J Adv Nursing* 2000; 32(6): 1431-1441.
16. Duggleby W, Degner L, Williams A, Wright K, Cooper D, Popkin D, Holtslander L. Living with Hope: initial evaluation of a psychosocial hope intervention for older palliative home care patients. *J Pain Symptom Manage* [in press].
17. Wennman-Larsen A, Tishelman C. Advanced home care for cancer patients at the end of life: a qualitative study of hopes and expectations of family caregivers. *Scand J Caring Sci* 2002; 16: 240-247.
18. Benzoin EG, Berg A. The level of and relation between hope, hopelessness, and fatigue in patients and family members in palliative care. *Palliat Med* 2005; 19: 234-240.
19. Dufault K, Martocchio B. Hope: its spheres and dimensions. *Nurs Clin North Am* 1985; 20(2): 379-391.
20. Synder C. *Handbook of Hope. Theory, measures, and applications.* San Diego: Academic Press, 2000.
21. Stotland E. *The Psychology of Hope.* San Francisco: Jossey-Bass, 1969.
22. Morse JM, Doberneck B. Delineating the concept of hope. *Image J Nurs Scholar* 1995; 27(4): 277-285.
23. Farran CJ, Herth K, Popovich JM. *Hope and Hopelessness: critical clinical constructs.* Thousand Oaks, California: Sage Publications, 1995.
24. Owen D. Nurses' perspectives of the meaning of hope in patients with cancer: a qualitative study. *Oncol Nurs Forum* 1989; 16(1): 75-79.
25. Nekolaichuk CL, Bruera E. On the nature of hope in palliative care. *J Palliat Care* 1998; 14(1): 36-42.
26. Sudani S, Braden C. *Evaluating nursing interventions. A theory-driven approach.* Thousand Oaks, California: Sage Publications, 1998.
27. Pennebaker J, Seagal J. Forming a story: The health benefits of narrative. *J Clin Psychol* 1999; 55(10): 1243-1254.
28. Krouse HJ. Video modeling to educate patients. *J Adv Nurs* 2001; 33(6): 748-757.
29. Gagliano ME. A literature review on the efficacy of video in patient education. *J Med Educ* 1988; 63: 785-792.
30. Aranda K, Hayman-White K. Home caregivers of the person with advanced cancer: an Australian perspective. *Cancer Nurs* 2001; 24: 1-7.
31. Aranda S. Caregiving in advanced cancer lay decision making. *J Palliat Care* 2001; 17(4): 270-276.
32. Chiverton E. Social support within the context of life-threatening illness. *Int J Palliat Nurs* 1997; 3(2): 107-110.
33. Jacelon C, Imperio K. Participant diaries as a source of data in research with older adults. *Qual Health Res* 2005; 15(7): 991-997.
34. Creswell J, Fetters M, Ivankova N. Designing a mixed methods study in primary care. *Ann Fam Med* 2004; 2(1): 7-12.
35. Birkett M, Day S. Internal pilot studies for estimating sample size. *Stat Med* 1994; 13: 2455-2463.
36. Herth K. Abbreviated instrument to measure hope: development and psychometric evaluation. *J Adv Nurs* 1992; 17: 1251-1259.
37. Cohen SR, Leis A, Kuhl D, Charbonneau C, Ritvo P, Ashbury FD. QOLLI-F: measuring family carer quality of life. *Palliat Med* 2006; 20: 755-767.
38. Patton M. *Qualitative Research and Evaluation Methods.* 3<sup>rd</sup> edition. Thousand Oaks, California: Sage Publications, 2002.
39. Addington-Hall J. Research sensitivities to palliative care patients. *Eur J Cancer Care* 2002; 11: 2002-2224.
40. Weitzner M, McMillan S. The caregiver quality of life index-cancer (CQOLC) scale: revalidation in a hospice setting. *J Palliat Care* 1999; 15(2): 13-20.



# AUTHORS AND CONTRIBUTORS

The following list arranged alphabetically provides names and addresses of those persons contributing to this issue of the Journal of Palliative Care. Note that affiliations and current addresses may have change since article submission.

**Anderson, Clarke, MD**  
Department of Pediatric Oncology  
City of Hope  
1500 East Duarte Road  
Duarte, California  
USA 91010-3000

**Brenner, Amy, RN**  
7407 Honesty Way  
Bethesda, Maryland  
USA 20817

**Cammer, Allison, MSc**  
Canadian Centre for Health and  
Safety in Agriculture  
University of Saskatchewan  
Wing 3E Royal University Hospital  
103 Hospital Drive  
Saskatoon, Saskatchewan  
Canada S7N 0W8

**Champagne, Manon, MA (ED)**  
Faculté des sciences de l'éducation  
Université du Québec à Montréal  
1664 boulevard Quinn  
Longueuil, Quebec  
Canada J4J 3J3

**Collins, John B., PHD**  
Department of Educational Studies  
University of British Columbia  
3631 Marine Drive  
West Vancouver, British Columbia  
Canada V7C 1N3

**Conley, Virginia M., PHD, APRN**  
Fay W. Whitney School of Nursing  
University of Wyoming  
1000 E. University Avenue,  
Department 3065  
Laramie, Wyoming  
USA 82071

**Cook, Karen, BScN, RN, MSc(A)**  
164 Chevere Street  
Oakville, Ontario  
Canada L6J 6C4

**Davies, Betty, RN, PHD, FAAN**  
Department of Family  
Health Care Nursing  
University of California,  
San Francisco  
School of Nursing  
2 Koret Way, Room N411-Y  
San Francisco, California  
USA 94143-0606

**Degner, Lesley E., RN, PHD**  
Faculty of Nursing  
Evidence Based Nursing Practice  
Room 312 Helen Glass  
Centre for Nursing  
University of Manitoba  
89 Curry Place  
Winnipeg, Manitoba  
Canada R3T 2N2

**Distler, Vivian, BA, LLB**  
3285 South Court  
Palo Alto, California  
USA 94306

**Dougherty, Elizabeth, MSW, RSW**  
Department of Psychosocial  
Oncology and Palliative Care  
Princess Margaret Hospital  
610 University Avenue, 16<sup>th</sup> Floor  
Toronto, Ontario  
Canada M5G 2M9

**Duggleby, Wendy, DSN, RN, AOCN**  
College of Nursing  
University of Saskatchewan  
107 Wiggins Road  
Saskatoon, Saskatchewan  
Canada S7N 5E5

**Dumitrescu, Luminita, MD, PHD**  
Str. Sg. Maj. Dorobantu C  
Nr. 2, Bl. A17, ap. 4  
Slatina 230113  
Romania

**Holtlander, Lorraine, MN, PHD**  
College of Nursing  
University of Saskatchewan  
107 Wiggins Road  
Saskatoon, Saskatchewan  
Canada S7N 5E5

**Kempson, Diane, PHD, MSW**  
Division of Social Work  
University of Wyoming  
1000 E. University Avenue  
Department 3632  
Laramie, Wyoming  
USA 82071

**Le, Lisa, MSc**  
Biostatistics Department  
Princess Margaret Hospital  
610 University Avenue, 15<sup>th</sup> Floor  
Toronto, Ontario  
Canada M5G 2M9

**Lee, Andrew, MD**  
Department of Otolaryngology  
University of California  
Davis Medical Center  
2521 Stockton Boulevard, Suite 7200  
Sacramento, California  
USA 95817

**Liben, Stephen, MDCM**  
Professor of Pediatrics  
McGill University  
The Montreal's Children's Hospital  
Room A418, 2300 Tupper Street  
Montreal, Quebec  
Canada H3H 1P3

**Lyren, Anne, MD, MSc**  
Rainbow Center for Pediatric Ethics  
Rainbow Babies &  
Children's Hospital  
11100 Euclid Avenue, Mail Stop 5016  
Cleveland, Ohio  
USA 44106

**Mongeau, Suzanne, PHD**  
École de travail social  
Université du Québec à Montréal  
Case postale 8888  
Succursale Centre-Ville  
Montreal, Quebec  
Canada H3C 3P8

**Panzarella, Tony, MSc**  
Biostatistics Department  
Princess Margaret Hospital  
610 University Avenue, 15<sup>th</sup> Floor  
Toronto, Ontario  
Canada M5G 2M9

**Phillips, Catherine, PHD**  
Portland Square, C422  
School of Applied  
Psychosocial Studies  
Faculty of Health and Social Work  
University of Plymouth  
Plymouth, Devon  
United Kingdom PL4 8AA

**Pierce, Bruce A., MA, CAPPE**  
CPE Centre  
Kerry General Hospital  
Tralee, County Kerry  
Ireland

**Rodin, Gary, MD**  
 Department of Psychosocial  
 Oncology and Palliative Care  
 Princess Margaret Hospital  
 610 University Avenue, 16<sup>th</sup> Floor  
 Toronto, Ontario  
 Canada M5G 2M9

**Rubin, David, BS**  
 Keck School of Medicine  
 University of Southern California  
 1975 Zonal Avenue  
 Los Angeles, California  
 USA 90089-9021

**Steele, Rose G., RN, PHD**  
 School of Nursing  
 Atkinson Faculty of Liberal and  
 Professional Studies  
 York University  
 4700 Keele Street  
 Toronto, Ontario  
 Canada M3J 1P3

**Swinney, Ryan, BS**  
 Keck School of Medicine  
 University of Southern California

1975 Zonal Avenue  
 Los Angeles, California  
 USA 90089-9021

**van den Heuvel, Wim, PHD**  
 Institute for Rehabilitation  
 Research (iRv)  
 University of Groningen  
 Heggerweg 2a  
 6176 RB Spaubeek  
 The Netherlands

**Wein, Simon, MD**  
 Department of Pain and  
 Palliative Care  
 Peter MacCallum Cancer Center  
 2 St Andrews Place  
 East Melbourne  
 3002 Victoria  
 Australia

**Williams, Allison, PHD**  
 School of Geography and Geology  
 McMaster University  
 1280 Main Street West  
 Hamilton, Ontario  
 Canada L8S 4K1

**Wright, Karen E., RN, PHD**  
 College of Nursing  
 University of Saskatchewan  
 107 Wiggins Road  
 Saskatoon, Saskatchewan  
 Canada S7N 5E5

**Yin, Lu, MD**  
 Department of Emergency Medicine  
 Brooklyn Hospital  
 121 Dekalb Avenue  
 Brooklyn, New York  
 USA 11201

**Zimmermann, Camilla, MD, MSc**  
 Department of Psychosocial  
 Oncology and Palliative Care  
 Princess Margaret Hospital  
 610 University Avenue, 16<sup>th</sup> Floor  
 Toronto, Ontario  
 Canada M5G 2M9