An inner struggle for hope: insights from the diaries of bereaved family caregivers

Lorraine Holtslander, Wendy Duggleby

Support for family caregivers, extending through bereavement, is mandated by international guidelines for palliative care (World Health Organization, 2002). The goal of bereavement support is to promote a successful transition and reintegration into society (Ferris et al, 2002) after the caregiving experience. Bereaved spouses experience difficulties with physical and mental ill health and an increased risk of mortality and morbidity from many causes (Stroebe et al, 2007). Therefore, it is important to increase our knowledge and understanding of their experiences during bereavement so that palliative care programmes can be adjusted and providers can improve the quality of care given to this vulnerable population.

A study of hope and bereaved family caregivers that involved open-ended interviews and the collection of hope diaries (Holtslander and Duggleby, 2008) was completed in 2007. The purpose of this article is to report the findings of a secondary content analysis of the hope diaries collected during the study. Although the data from the diaries were integrated into the grounded theory findings of the study, they were not reported in depth. The secondary analysis was undertaken to add a unique, insider’s perspective of the day-to-day hope experience of the bereaved palliative caregiver.

Background

Hope was a psychosocial resource that family caregivers used to deal with a difficult, stressful, but personally significant, caregiving experience (Herth, 1993; Borneman et al, 2002). Family caregivers of a palliative cancer patient defined hope as an inner strength and courage to go through a difficult situation (Holtslander et al, 2005). In a study of older, grieving widow(er)s, hope was positively correlated with, and accounted for 79% of the variance in, grief resolution (Herth, 1990).

Bereavement is a time of great difficulty, particularly for the older caregiver of a palliative cancer patient. In a study of 248 bereaved palliative caregivers, 50% indicated their need for bereavement follow-up (Milberg et al, 2008). The participants wanted to talk about their experiences of caregiving, their feelings of loneliness, and the future. Most family caregivers of palliative patients are older women, entering bereavement after an often lengthy and difficult caregiving experience, who may themselves have health problems. For these reasons, the authors studied the experience of hope of older women who were bereaved family caregivers of persons with advanced cancer.

The overall findings of the original grounded theory study suggested that participants were searching for new hope and their main concern was losing hope. The processes involved were finding balance, finding new perspectives, and finding new meaning and purpose. The interviews and the diaries were analyzed together using constant comparative methods, although it was not possible to include all of the hope diary data. Further in-depth content analysis of the diaries revealed insights into the inner
processes of hope, and the particular ways in which hope was hindered and fostered. The specific aims of this secondary analysis were to: a) to explore the overall experience of hope as described in the diaries and b) to describe the specific hindrances to hope and c) to identify the ways participants were able to foster their own hope.

Method

Design
The overall purpose of the initial study was to explore the experience and processes of hope for a unique population and the hope diaries emerged as an important part of this (Holtslander and Duggleby, 2008). The participants were asked to complete a hope diary after the first interview, which was collected at a second interview two weeks later. A written diary can encourage frank disclosure and provide unique insights that are different from interview data (Charmaz, 2006). Diaries were used with older adults to successfully obtain rich data, written or taped, for a short time each day, over a recommended time frame of one to two weeks (Jacelon and Imperio, 2005). During the process of completing the study, it became apparent that writing in the diary had an effect on the participants. They described specific insights as a result of writing about hope in a diary each day, and this was reflected in their words and actions as observed and reported at subsequent interviews. The diaries became a tool for the participants to find ways to foster their own hope. A content analysis of these diaries was completed to make sense of this qualitative material and to identify core consistencies and meanings (Patton, 2002).

Sample
The sample for the original study comprised older, female, spousal caregivers of a deceased palliative cancer patient. Inclusion criteria were that participants should be women aged 60 years and over, who resided with and provided care to a spouse with terminal cancer. They should also be English-speaking, and freely consent to be a participant in a research project about hope in bereavement. Exclusion criteria were: cognitive impairment, non-autonomy, or inability to give free and informed consent.

Purposive sampling techniques were employed to select participants from a variety of ages over 60 years, different lengths of caregiving, and support situations. Table 1 shows the demographic characteristics of the study participants. Most participants were interviewed twice; five were interviewed three times. Twelve diaries were collected, one from each participant, except for one who died before a second interview could be arranged. Eleven diaries were written and one was taped. There was an average of 13 entries in each. They varied in length, from several lines to a page each day. The twelve diaries contained a total of 11,535 words.

Procedures
The diaries were part of the original study that was approved by an institutional review board and the local health region’s ethics committee. Procedures to ensure informed consent and participant confidentiality were strictly adhered to. The co-ordinator of volunteers of the local health region’s palliative programme contacted potential participants and asked if they would be willing to talk with a nurse researcher about the study. The participants were then contacted by the researcher to arrange a time to meet with them in their home. The study was explained

Table 1. Demographic characteristics of the participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number</th>
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<tbody>
<tr>
<td><strong>Age:</strong></td>
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<td>60–69 years</td>
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<td>70–79 years</td>
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<td>Caucasian</td>
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<td><strong>Religious preference:</strong></td>
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<td>Protestant</td>
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<tr>
<td>None</td>
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<tr>
<td>Catholic</td>
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<tr>
<td><strong>Years of education completed:</strong></td>
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<td>8–12 years</td>
<td>7</td>
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<td>13–16 years</td>
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<tr>
<td><strong>Primary diagnosis of patient:</strong></td>
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<tr>
<td>Lung cancer</td>
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<tr>
<td>Unsure of primary cancer</td>
<td>3</td>
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<tr>
<td>Lymphoma</td>
<td>2</td>
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<td>Pancreatic cancer</td>
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<td>Prostate cancer</td>
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<tr>
<td>Kidney cancer</td>
<td>1</td>
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<td><strong>Length of caregiving:</strong></td>
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<td>1–3 months</td>
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<td>4–6 months</td>
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<td>7–12 months</td>
<td>3</td>
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<td>More than 12 months</td>
<td>3</td>
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<tr>
<td><strong>Main support system:</strong></td>
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<tr>
<td>Children close by</td>
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<tr>
<td>Children out of town</td>
<td>3</td>
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<tr>
<td>Friends</td>
<td>2</td>
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<td>Other relatives</td>
<td>2</td>
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<td><strong>Months since death of the patient:</strong></td>
<td></td>
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<tr>
<td>3–6 months</td>
<td>3</td>
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<tr>
<td>7–9 months</td>
<td>7</td>
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<tr>
<td>10–13 months</td>
<td>3</td>
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and written, informed consent was obtained before the first interview. The researcher provided either a small booklet, labelled as a hope diary with instructions inside, or a tape-recorder at the first interview. The participants were asked to take five minutes at the beginning or end of every day to think about and describe what hope meant to them that day, and what actions, activities, or specific supports hindered or helped their hope. The diaries were collected by the researcher, photocopied or transcribed, and returned. The diaries were transcribed verbatim and a content analysis was completed to reveal the study findings.

Data analysis and interpretation
The data from the hope diaries were analyzed using Patton's (2002) content analysis methods. Description and interpretation of the data were completed with the goal of extracting meanings from the data, making comparisons, and drawing conclusions about the overall experience of hope and what hindered and what fostered hope. The patterns in the data were sorted into an analytic framework which made sense of all the data, drew out the most significant results, and identified core meanings. The inductive analysis involved developing a coding scheme, comparing, categorizing and labelling the patterns in the data. Quality and credibility were sought by gathering rich data from multiple sources and transcribing the diaries verbatim. An audit trail of the research, from raw data to analysis and interpretation was kept. A description and interpretation of the study findings will be presented concurrently with a discussion of relevant research literature.

Findings and discussion
The study participants described their hope as a feeling of peace, courage, strength, and self-confidence that enabled them to face each day, as well as an uncertain future, with a positive outlook. Their hope was to deal with the loss of their spouse, to regain confidence, and to be able to reach out to others. Their hope was also for their families. One participant wrote:

‘My hope is that we will be able to face each new day doing the best we can do and being able to cope without him.’

Another participant wrote:

‘What Hope meant to me: that someday I could go from grief to joy to be able to have pride and regain my self-confidence. To achieve and finally have something to give to others as others have been giving me.’

One participant summed up her hope experience as follows:

‘I think it is too early to really feel much hope for myself and the hope I have for my family is the same as it always has been. Hope for their health, safety and wellbeing.’

Hindrances to hope
The participants were asked to write about what hindered their hope each day. By coding and categorizing these data, such hindrances were identified and labelled. Each of these categories influences each other and is difficult to separate.

Multiple losses
The participants experienced multiple losses, including a spouse, a life partner, and a caregiver, and some lost their homes. The loss of a partner was described by one participant as a ‘challenge to my hope. I am now a widow. My life has changed.’ It was difficult to face the loss of this relationship. One wrote:

‘All the self that you invest into a relationship you hope with all your heart that there is some way you could have it back.’

Another wrote: ‘Missing [spouse], thinking my life will never be the same. Feel sad that the grandchildren lost their grandpa so soon.’ One participant wrote about sleeping alone:

‘I miss him in my bed. I miss the excitement of being with [spouse’s name] he was stimulating in every way, in conversation in bed and just being together.’

One wrote about her visit to the cancer center and the loss of a caregiver:

‘These are the times I really miss my [spouse’s name]. He drove me to every doctor’s appointment – waited and fretted with me.’

These results are similar to a grounded theory study of hope with ten palliative patients; the
multiple losses in their lives began the process of transforming hope (Duggleby and Wright, 2005). Hope enabled the participants to come to terms with their losses, to acknowledge or accept ‘life the way it is’. The loss of a spouse represents more than just an emotional upheaval. In research with 1,532 older participants, multiple losses affected nearly every facet of their lives, including daily practices and routines that provided stability and purpose (Utz, 2006). Further research is needed to determine how the number and type of losses influence hope and how the needs of bereaved persons who face multiple losses can be addressed from a holistic perspective.

**Loneliness**

The loneliness the participants experienced had a major impact on hope, as one participant wrote: ‘Hope hindered by loneliness.’ Certain times of the day, week, and year were more difficult. Participants wrote: ‘Weekends are always the worst,’ and, ‘The thought of another special occasion without [spouse’s name] is really bothering me.’ This is similar to a grounded theory study of 34 bereaved adults (Hogan et al, 1996); ‘missing, longing, and yearning’ were associated with feelings of sadness, helplessness, and hopelessness.

**Physical health concerns**

Many participants described their physical health in the diary as it hindered their hope. Fatigue, lack of energy, difficulty sleeping, infections, blood pressure and heart problems, anxiety, and depression were recorded in the diaries. One wrote about her exhaustion: ‘I hope I can get myself out of bed and, and um, go and do what I have to do.’ Another wrote: ‘My chest seems better, perhaps the antibiotics worked after all.’ Another described: ‘My fatigue stayed with me all day today.’ Each of them was recovering from the exhaustion of caregiving and may have put off seeking medical help during caregiving.

Previous research has identified the impact of bereavement on physical health. In a sample of 1,532 older persons, the stress of losing a spouse later in life predicted increasing difficulties in physical functioning, an effect that did not diminish over the 48 months of the study (Lee and Carr, 2007). Increased fatigue correlated with decreased hope for caregivers of palliative cancer patients (Benzein and Berg, 2005). A mixed-method experimental design testing the effectiveness of a hope intervention for older palliative patients showed a significant effect on quality of life and hope (Duggleby et al, 2007). The group receiving the hope intervention had higher scores of physical wellbeing. More research is needed on the connections between hope, the fatigue from caregiving, and its effects on physical health in bereavement.

**Fostering hope**

The categories that emerged from an analysis of the ways in which participants fostered their hope were by ‘positive thoughts’, ‘connections’, and ‘taking care of physical needs’. Each of these relates to the categories that hindered hope (Table 2).

**Table 2. Findings: what hinders and fosters hope?**

<table>
<thead>
<tr>
<th>Hinders hope</th>
<th>Quote</th>
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<tbody>
<tr>
<td>Multiple losses</td>
<td>‘Challenge to my hope. I am now a widow. My life has changed’</td>
</tr>
<tr>
<td>Loneliness</td>
<td>‘Hope hindered by loneliness’</td>
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<td>Physical health concerns</td>
<td>‘My fatigue stayed with me all day’</td>
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<table>
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<tr>
<th>Fosters hope</th>
<th>Quote</th>
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<tr>
<td>Positive thoughts</td>
<td>‘I try to be positive’</td>
</tr>
<tr>
<td>Connections</td>
<td>‘Maybe this is where hope enters our lives as between us we can try to comfort each other’</td>
</tr>
<tr>
<td>Taking care of physical health</td>
<td>‘I had a wonderful sleep and felt positive and hopeful when I woke up’</td>
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**Positive thoughts**

The hope diaries contained many entries describing the importance of positive thoughts, mostly through being grateful and appreciative of others in their lives, although a great deal of energy and inner strength was required. One participant wrote:

‘I try to be positive, hang on to your memories, appreciate my family and friends, I know they care.’

Another participant faced a difficult experience and wrote:

‘I know now that no matter how or what I feel I will not let myself be self-absorbed or expect pity.’

A participant wrote: ‘The first step to hope is being thankful.’ Another summed up her experience of writing in the diary as: ‘Think positive and things are better!’ The literature is supportive of the relationship between positive thoughts and hope. Positive reappraisal was a process by which
elderly palliative persons were able to change their hope (Duggleby and Wright, 2005). In another grounded theory study of hope and family caregivers of palliative patients, ‘staying positive’ was a sub-process of ‘hanging on to hope’ in challenging and difficult situations (Holtslander et al, 2005).

**Connections**

Participants’ connections to family, friends, nature and faith were identified as essential to foster hope. By surrounding themselves with family, friends, professionals, and even pets, participants were able to relieve loneliness and foster hope in their lives. One wrote: ‘Family is hope,’ and another wrote: ‘Kindness gives you hope.’ The participants described the importance of sharing with others, as one participant wrote:

‘Maybe this is where hope enters our lives, as between us we can try to comfort each other.’

The importance of relationships to hope during bereavement has been found in other research; specifically, the trusting relationship with a counsellor was an essential process of regaining hope (Cutcliffe, 2006). However, the complexity of social support in widowhood was identified in a mixed-methods study of 20 older widows (Scott et al, 2007); important individual differences may be regulated by perceived social control. Widows were disappointed when the support they expected was not available.

Many participants described the importance of connections with their own faith and with nature. One participant wrote:

‘There is nothing like the Scriptures to give you hope for tomorrow and peace for today.’

Another wrote:

‘Hope’ is feeling God’s presence with me at all times to help me deal with my bereavement. I thank God for being with me to help me accept his loss.’

The relationship between hope and connections has been discussed in the literature. In a mixed-methods study of 51 family caregivers of palliative cancer patients, hope stemmed from faith, connections with God and with others (Borneman et al, 2002). Similarly, in a grounded theory study of the experience of hope for family caregivers of palliative patients, connecting with something bigger and stronger, and positive relationships, were essential processes of ‘hanging on to hope’ (Holtslander et al, 2005). Ongoing research is needed to explore the relationships between connections, faith, spirituality, and hope.

**Taking care of physical needs**

The diaries contained many entries in which participants described walking, exercising, sleeping, and visiting their physicians:

‘I went for a walk today with [name]. The first time in a long while. It felt good.’

‘I am so fortunate to have a dog to take for walks, I can talk to her and fresh air and a walk makes me feel better.’

‘Slept in this morning – what a wonderful change. Finally getting back to not having trouble sleeping. I had a wonderful sleep and felt positive and hopeful when I woke up.’

A study of a breathing and stretching exercise intervention with middle-aged bereaved widows in Korea showed statistically significant differences in the treatment group for grief levels but no difference in immune response (Kang and Yoo, 2007). Further research is needed to understand the relationship between exercise, physical care, and hope during bereavement.

**Writing in a diary**

Participants described how writing in the diary helped them to realize and learn about their own emotions, thoughts, and actions, since they may not have been aware of their inner struggle for hope. For example, one participant described the effect of writing in a hope diary:

‘Can’t believe the number of ups and downs I have in a day since writing in this journal. Would have said my life was going along great, and it is for the most part. The knowledge will help me continue to heal, I’m sure.’

The diaries offered each participant a time for reflection and helped them to identify areas of difficulty. One participant wrote:

‘It has been very interesting to do this diary. I have learned a lot about myself, how to deal with problems I encounter and how to relax and enjoy each minute of each day.’

Another participant summed up the diary in the following way:

‘I had never really thought about hope. All I knew is that when I think back over the last
nine months, how I felt when [spouse’s name] first passed away, I couldn’t think, all I could feel was pain with his loss. It was like I was in this black hole and I didn’t want to come out. As the months passed I knew life would still go on for me, and I had to try to make the best of it – for me and my family – that is what [spouse’s name] wanted me to do. I know I’ll have bad days, but I also know things will get better and easier and I should be grateful I’m here to feel them both.’

This concurs with previous research demonstrating the impact of writing to generate significant health improvements (Pennebaker and Chung, 2007). In a writing therapy study of 69bereaved family members in Australia, both the intervention and control groups had similar improvements in their level of grief and general health, no statistically significant differences were found between the groups (O’Connor et al, 2003). However, the small and heterogeneous sample, which ranged in age from 31 to 86 years, may have affected the results. They also may have already received grief intervention; interestingly, 25% were already keeping a journal. Further research is needed to evaluate writing as an intervention for bereaved caregivers in various circumstances, including those who are most vulnerable.

**Limitations**
The context of the study, the methodology, and the chosen sample had an influence on the findings of this study. The sample was from a small Canadian city, offering support to caregivers through bereavement. The methodology was a secondary analysis of the hope diaries; participants wrote about their daily hope experience from their own perspective. The sample comprised older women, experiencing many secondary losses and physical changes, although variation was sought in their ages, lengths of caregiving and support systems. Studies of people from different geographic locations, other ages and genders, and cultural groups would provide differences in their experience and processes of hope.

The participants were willing to write in a diary each day, and perhaps participants who were having a more difficult time would have provided another perspective. These findings need to be interpreted and adapted to each situation.

**Implications for practice/research**
Nurses have an important role in providing supportive care that promotes a healthy adjustment to loss during bereavement. Realizing the importance of hope for the bereaved family caregiver and the circumstances that may be hindering hope is a good first step when a nurse meets a caregiver in a primary care situation, when the caregiver is a patient themselves, or in routine bereavement follow-up. The nurse could provide an opportunity for the bereaved caregiver to identify and support ways to stay positive, to make connections, and to take care of their physical health as ways to facilitate hope. Ongoing research is needed with a variety of populations and settings to develop theory from which to build and pilot a hope intervention for bereaved caregivers.

**Closing thoughts**
It may be easy to ignore the inner struggles for hope experienced by the bereaved palliative caregiver in the competing demands of a busy palliative care service; however, the nurse’s obligation is to provide support and promote health after caregiving ends. The bereaved caregiver is recovering from the exhaustion of caregiving while dealing with multiple losses, loneliness, and their own physical health. The content analysis of the hope diaries provides a framework to foster hope and offers a unique insight and an opportunity for effective and compassionate care focused on promoting a positive adjustment after caregiving ends. The hindrances to hope – multiple losses, loneliness, and physical health concerns – need to be recognized and intervention provided if possible. As nurses engage with bereaved family caregivers, fostering hope is an important aspect of compassionate and effective care.

This dissertation research was completed at the University of Saskatchewan, College of Nursing. We owe sincere gratitude to the study participants, and to Meredith Wild, Manager of Palliative Services, and Sacha Tegenkamp, Coordinator of Volunteers, with the Saskatoon Health Region, and Eleanor Edwards of the Saskatoon Funeral Home for their assistance in recruiting the participants. Funding for this study was received from the Saskatoon Association of Loss, Grief, Education and Support.


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