The chaos of caregiving and hope

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Abstract
Hope is an important psychosocial resource that has been found to support family caregivers. In order to further understand the challenges of caregivers and their hope experience, we analyzed, using Cortazzi’s (2001) narrative analysis approach, 101 journal entries of family caregivers of persons with advanced cancer. The data was condensed into poetic phrases to reflect structural categories outlined by Cortazzi of event, description and evaluation resulting in a poetic narrative entitled ‘The Chaos of Caregiving and Hope’. Each stanza of the poetic narrative describes the day-to-day experiences of the participants’ chaos and hope. We believe that looking at the caregiving experience through poetic presentation provided new insights into the lives of caregivers caring for terminally ill cancer patients. These insights are related to the intensity of the chaos, and how hope is present in their daily lives.

Keywords
end of life, family caregivers, hope, poetic narrative

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The Chaos of Caregiving and Hope
I had a normal life once, but things have changed.  
It was unexpected – my life is chaos  
In my naivety, I believed I could do this  
I underestimated the illness that accompanied my companion.

The illness my companion bears is often silent in its demands.  
Sometimes I am able to imagine it to be harmless.  
Its true nature is just beneath the surface,  
Ready to drain the life from us both.

I have no map, no directions, no guide,  
This is an incredible challenge I am unprepared for.  
We discuss better days gone by to boost our spirits.  
Family and friends sometimes join us – I have hope for better days.

Often my mood is connected to the weather.  
When the sun is shining the days seem brighter  
I stop to enjoy life’s beauty and to smile – I find hope.  
I am temporarily distracted from the chaos of our lives.

Cloudy, stormy days bring with them dark, depressing moods.  
Fear creeps into my heart – I feel angry and helpless  
Before, when something was broke I fixed it, but I can’t fix my companion.  
I feel disconnected from my life – can I get it back?

My companion’s life force is draining bit by bit.  
Sometimes my companion is too weak – I consider life alone.  
This thought brings with it a tidal wave of relief  
And guilt that combine to overwhelm me.

The days extend in an endless stretch  
There is no end in sight! How long can I go on?  
We’re running low on supplies  
A crisis is coming – Help I don’t know how to do this!

Others offer to care for my companion  
I feel guilty for even wanting to have a rest  
My internal battle continues – I secretly yearn to be me again.  
In the end my hope that I can make a difference returns.

I write my challenges, fears and hopes in my journal.  
Putting thoughts and feelings to paper gives them life and hope shines through.  
Sharing my journals with others gives me the feeling that someone is walking
with me.
Reading my own words reassures me that I have done all I can and I have no regrets.

Every day I cling to hope.
It anchors me in the belief that we will find peace
Every new morning brings new hope to get through the day.
I live day by day to its fullest.

The poem ‘Chaos of Caregiving and Hope’ was created from journals collected as part of a pilot study evaluating a hope intervention for family caregivers of terminally ill cancer patients ($n = 10$). The purpose of the pilot study was to evaluate the intervention for ease of use and feasibility. The evaluation findings of the hope intervention are reported elsewhere (Duggleby, Wright, Williams, Degner, Cammer and Holtslander, 2007). The participants’ written journals were analyzed to describe the challenges and hope experienced by family caregivers of persons with advanced cancer.

Although hope has been described by family caregivers as very important in their lives, only a few studies have contributed to our understanding of the hope experience of family caregivers of persons with advanced cancer (Duggleby, Kylma, Holtslander, Duncan, Hammond and Williams, 2010). In a recent meta-synthesis study of the hope experience of family caregivers of persons with chronic illness, 14 studies were identified (Duggleby et al., 2010) of which only two focused on the hope experience of family caregivers of persons with advanced cancer (Borneman, Stahl, Ferrell and Smith, 2002; Holtslander, Duggleby, Williams and Wright 2005). Although these studies have added to our understanding of the hope experience, many questions remain about the hope of family caregivers’ living with and caring for someone who is dying with advanced cancer. The purpose of this article is to describe the experience of family caregivers of persons with advanced cancer by reporting the findings of a planned narrative analysis of participants’ journals collected as part of a pilot study.

**Data collection**

We collected 101 journal entries from six women and four men living with and caring for family members with advanced cancer at home. Participants had engaged in a directed written journaling exercise once a day for two weeks as part of the hope intervention. They were asked to focus on their experiences that day, their challenges and what gave them hope. At the end of the two weeks the journal entries were photocopied with written permission from the study participants for analysis. The journals were then returned to the study participants. An ethics review board approved the study and written informed consent was obtained from the study participants and the family member they were caring for.
Participants

The majority of the study participants were older (mean age 60.3 years, range 38–87), female, well educated (mean years of education 13.5, range 10–16), and with a range of incomes (less than $10,000 a year to more than $60,000). The sample consisted of four husbands, three wives and three daughters. The participants generally reported no medical conditions and good health status. The majority of the persons the study participants were caring for were older (mean age 69.4 years, range 45–89), all had a diagnosis of cancer and were receiving palliative home care services in a rural area in a western Canadian province.

Data analysis

An experienced transcriptionist transcribed the journal writings verbatim and assigned each participant a code number and replaced any names used in the journals with pseudonyms to ensure confidentiality. Several steps were involved in the data analysis. The first step in the analysis of the journals was to determine the type of narrative represented in the data using Frank’s (1995) criteria. Frank has identified three types of narratives: restitution (all can be restored), chaos (all is lost) and quest (deeper meaning will arise from suffering). The type of narrative is a reflection of the substantive material that has been the focus of the narrative. Frank suggests that determining the type of narrative facilitates closer attention to the stories themselves and facilitates sorting out the story threads. To determine which type of narrative the journals represented, the transcripts were read and re-read as a whole.

The journal data were analyzed using the procedures of narrative inquiry as described by Cortazzi (2001). Narrative inquiry has been utilized in social science and human disciplines to access study participants’ understanding of key events in their lives and how they organize their understanding of the world. Cortazzi suggests that there are three major structural categories of a narrative: event, experience and evaluation. The event structure describes an event or series of events that have happened. Experiences are the images, reactions, feelings and meanings ascribed to recounted events and the narrative evaluation reflects the participants’ interpretation of the events.

In our analysis, transcribed data from the participants’ journals were sorted into Cortazzi’s (2001) three major structural categories (i.e., event, experiences, and evaluation). Overlap in the data was synthesized by compressing the points of many participants into concise phrases representative of the structural category of the narrative, staying as true as possible to the participants’ words. As poetry may be a means of enhancing and giving power to voices (Glesne, 1997) we chose poetic form to present the findings of the analysis. Using Glesne’s (1997) approach to guide the process of poetic transcription, the words in the poetic transcription were those of the participant as much as possible. The poetic phrases chosen represented the findings of each of Cortazzi’s (2001) structural categories (event,
experiences and evaluation). We organized the compressed phases into stanzas to provide a sense of coherence to the participants’ thoughts. Stanzas were used to divide the narrative into groupings that were then ordered according to event, experience and evaluation to enhance the poetic flow of the participants’ narratives.

Findings

The narratives of the family caregivers represented stories of chaos. Chaos stories are characterized by their absence of narrative order (Frank, 1995). In chaos narratives, events are told as the storyteller experiences life without sequence of discernable causality. The reader is ‘swept along, without control, by life’s fundamental contingency’ (1995: 102). Stories of chaos are hard to listen to because they are anxiety provoking. After reading the participants’ journals we felt they clearly reflected stories of chaos as the participants’ caregiving experience was without sequence and causality and was anxiety provoking.

Through the process of analysis and interpretation we developed a poetic narrative entitled ‘The Chaos of Caregiving and Hope’. Each stanza describes the day-to-day experiences of chaos of the study participants together with their reflective evaluations of hope and the challenges of providing care for a family member with advanced cancer. Table 1 illustrates examples of how we condensed the journal verbatim transcriptions into poetic phrases for each structural category of event, description and evaluation. The poem was written in first-person as suggested by Arvay (1998) to engage the reader and bring to life multiple interpretations.

Reflections

All participants were experiencing caregiving to a family member dying from cancer from a different personal perspective, yet a common experience emerged through their stories, that of chaos and hope. All the participants reflected on the events of their lives before their family member was diagnosed with cancer: For example the phrase ‘I had a normal life once’ was chosen to represent one aspect of their previous life. They described how their life was thrown into chaos when they unexpectedly became caregivers. Each person embarked on caregiving not knowing what to expect, or how they were going to handle the daily challenges of caregiving. Examples of these challenges included physical and emotional exhaustion of looking after someone who is terminally ill on an ongoing basis, loss of their previous identity as their role of caregiver consumed them, frustration and anger over their situation, struggles with financial resources, and mixed feelings of guilt and relief during respite times. The participants were unable to make sense of the chaos that they were experiencing which reflects Frank’s (1995) description of a chaos narrative. Despite all their confusion and uncertainty, they continued day-by-day searching for hope to assist them in dealing with their daily challenges and fears.

‘The Chaos of Caregiving and Hope’ reflects the transitions of the caregiving experience, the ongoing nature of uncertainty, fear, distress, joy and hope of the
Table 1. Examples of comparison between verbatim journal transcription and poetic narrative condensation

<table>
<thead>
<tr>
<th>Verbatim Journal Transcription</th>
<th>Poetic Narrative Condensation</th>
</tr>
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<tbody>
<tr>
<td><strong>Journal Event</strong></td>
<td></td>
</tr>
<tr>
<td>It is now that it is more apparent than ever that our lives have changed in a very major way. Our normal routines no longer apply and we struggle to redefine what is normal for us.</td>
<td>I had a ‘normal’ life once – Then things changed!</td>
</tr>
<tr>
<td>I remember our better days gone by – the good and happy things that happened to us – some of the great people we have met in our work... there were many things I used to do for our work and friends, but I can’t do much to help these days.</td>
<td></td>
</tr>
<tr>
<td><strong>Journal Description</strong></td>
<td>Poetic Description of Experiences</td>
</tr>
<tr>
<td>Every day is a greater challenge we are unprepared for.</td>
<td>This is an incredible challenge we are unprepared for.</td>
</tr>
<tr>
<td>The family came and we all had an enjoyable time talking and drinking tea – just like old times.</td>
<td>Family and friends sometimes join us.</td>
</tr>
<tr>
<td>Hope – I hope for a better day tomorrow.</td>
<td>Hope for a better day.</td>
</tr>
<tr>
<td>It stormed today – moods were at a low ebb.</td>
<td>Often my mood is connected to the weather.</td>
</tr>
<tr>
<td>Warm, sunny, it was great to be outside!</td>
<td>When the sun is shining the days seem brighter.</td>
</tr>
<tr>
<td>A dark depressing day emotionally. There is not much hope in this life.</td>
<td>Cloudy, stormy days bring with them dark, depressing moods.</td>
</tr>
<tr>
<td>Help! I’m tired. I feel trapped! A crisis is coming and I don’t feel up to handling it.</td>
<td>I feel a crisis coming and I don’t know how to do this.</td>
</tr>
<tr>
<td>I’m feeling very helpless and angry at the world.</td>
<td>I’m feeling very helpless and angry at the world.</td>
</tr>
<tr>
<td>The pipe in the basement broke today and I fixed that, but I can’t fix her.</td>
<td>Before, when something was broke I fixed it, but I can’t fix my companion.</td>
</tr>
<tr>
<td>I have always been able to help with any problem, but this is so hard knowing I can only be there for her and nothing else.</td>
<td></td>
</tr>
<tr>
<td>I feel disconnected from my life... as time passes</td>
<td>As time passes, I feel disconnected from my life – can I get it back?</td>
</tr>
<tr>
<td>I feel more and more removed from it all and wonder if I will regain it?</td>
<td></td>
</tr>
<tr>
<td>Is there no end to this?</td>
<td>There is no end in sight!</td>
</tr>
<tr>
<td>Because I’m staying home to care for her we have no income. Each and every day is a challenge on how we will make do.</td>
<td>We’re running low on supplies.</td>
</tr>
</tbody>
</table>
caregiving experience for those living with and caring for a family member with advanced cancer. In other studies transitions of roles as a family caregiver have been described as a time of uncertainty and turbulence (Wennman-Larsen and Tishleman, 2002). Although similar in concepts, the stories of chaos in our study’s poetic narrative speak to uncertainty and turbulence throughout the caregiving experience not only related to transition in roles. Transitions are processes of change during which a new situation or circumstance is incorporated into the life of a person (Olsson and Ek, 2002). Theories of transition suggest that as the new situation is incorporated into the life of the person, there is a redefinition of what is considered normal (Melies, Sawyer, Im, Messias and Schumacher, 2000; Selder, 1989). Our findings suggest that for the study, participants redefining normal may have not yet occurred as their stories were chaos narratives.

<table>
<thead>
<tr>
<th>Table 1. Continued</th>
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<tbody>
<tr>
<td>Verbatim Journal Transcription</td>
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<tr>
<td>I’m 66 and on duty from 8am to midnight 24/7 – how can a person keep it up and for how long? I guess the health aids give me hope to know that I can share my burden with them. I feel guilty for even wanting to have a rest. How will it all end? I need to take better care of myself... and I’ve only been here six weeks! VV responded in a positive way to my overtures of help this evening. He gave me hope that I will be able to make a difference for his quality of life.</td>
</tr>
</tbody>
</table>

Journal Evaluation

By writing this journal for the study, I feel like someone else is walking with me and my personal thoughts through this journal. I’m not sure what the future hold but I do know that I have to just remember that I have done all I can and I have no regrets. Hope? Maybe it will be a better day tomorrow for her – there ought to be some good or better days for her yet. Hope does peek through and I am secure in the knowledge that I will not be given more than I can handle and there are brighter days ahead. Tomorrow is a new day! We live day-by-day at its fullest. But our hope is strong. I know we cannot cure the cancer, but we can buy time for us. |

Poetic Evaluation

Sharing my journals with others gives me the feeling that someone is walking with me. Reading my own words reassures me that I have done all I can and I have no regrets. Everyday my companion and I cling to our hope. Every new morning brings new hope to get through the day. I live day-by-day to its fullest.
The participants in our study described the lack of information and resources to assist them with their experience. The caregivers’ lack of knowledge of caregiving and general lack of support for caregivers has also been reported in other studies. In focus group discussions with palliative caregivers feelings of unpreparedness for their role were described (Hudson, Aranda and McMurray, 2002). In studies of caregivers caring for family members at home, participants have described feelings of fear, anger and helplessness associated with the progression of illness and their struggle to obtain the services they needed for their family member (Milberg, Strang and Jakobsson, 2004). The lack of resources for caregivers has resulted in feelings of burden, fatigue, uncertainty and guilt similar to what was described by our study participants (Christakis and Iwashyna, 2003; Given, Wyatt, Given, Sherwood, Gift, DeVoss and Rahbar, 2004; Harding and Higginson, 2003; Hull, 1992). However, in these studies the lack of support for caregivers, and emotional responses to caregiving were not integrated with feelings of hope. Our study findings suggest that hope is integrated along with feelings of uncertainty and guilt which occurs within the everyday experience of family caregivers.

Study participants described their hope in relation to reminiscing about past experiences, sharing their experiences with others, writing in their journals and living day by day. Their hope was for better days and to continue caregiving. Although living day by day has been described as a way to foster hope, in another study of hope of family caregivers of persons with advanced cancer (Holtslander, Duggleby, Williams and Wright, 2005), reminiscing, sharing experiences with others and writing in journals has not yet been described in other hope studies of family caregivers. Reminiscing has been found to foster hope in terminally ill cancer patients (Duggleby and Wright, 2009) and may be an important strategy for family caregivers as well.

Factors influencing the study

We created ‘The Chaos of Caregiving and Hope’ from data in written journals collected as part of a hope intervention in a pilot study. The written journals did not allow us to gather in-depth data that may have been obtained through interviewing and the results were not confirmed with the study participants. The journaling in this study was not open-ended, but directed as a five-minute exercise to be completed at the end of the day where the participants were to write about their challenges and hope that they had experienced that day. This may have limited the free flow of ideas of the study participants. However solicited diaries or journals do encourage the participants to focus on daily activities and reflections that study participants value (Jacelon and Imperio, 2005). The process of writing narratives is a different form of sense-making than oral interviews and is conscious-raising (Nygren and Blom, 2001). Pennebaker and Seagal’s (1999) research suggests that writing promotes making sense and finding meaning and purpose in difficult situations.
Another factor influencing the study is that we used a narrative inquiry methodological approach and then formed a poem from the data representing the findings of the analysis. In transforming the data into poetry, there is the potential that the voices of the participants are lost in the interpretation. For this reason we used the words from the participants as much as possible to form the stanzas of the poem. Furhman (2006) suggests that using this type of approach to poetry means that poetry was not imbedded in the structure of the study resulting in a different poetic representation than would occur if data was collected as poetry. Also, the poem represented data compiled from more than one person, which may lose the individual interpretation of their experience (Carr, 2003). However, the purpose of this study was to use a narrative approach to gain a more nuanced understanding of the challenges of caregiving and hope experienced by those caring for persons with cancer. Narrative inquiry is appropriate for studies whose purpose is to interpret and make sense of events infused with multi-layered meanings (such as caregiving and hope) arising from the expression of personal experiences (Bingley, Thomas, Brown, Reeve and Payne, 2008). It is a way of exploring the understanding of an individual’s story within the life and culture in which it is created (Clandinin and Rosiek, 2007). As such the readers are able to enter into the participants’ stories of chaos and hope and gain an understanding of caring for a family member with advanced cancer.

Conclusion

Looking at the caregiving experience using narrative inquiry and through poetic presentation provides a nuanced understanding of the lives of caregivers caring for persons who are terminally ill and illustrates the intensity of the chaos, and hope present in their daily lives. The study adds to our understanding of the hope and caregiving experience in several ways. For example, reminiscing, sharing experiences with others and journaling may help with fostering the hope of family caregivers.

Capturing the responses or reactions of the study participants in the poem, based on their journals, provides an interpretative confirmation of the caregivers’ experience. Health care professionals may use the poem as a discussion point with other caregivers as it may provide confirmation to others’ experiences, or further discussion of how their own experience is different. Also the findings suggest possible strategies that may foster hope, such as reminiscing, sharing experiences and journaling. However these strategies require future research to determine if they are effective in fostering hope in this population.

The multiple complex transitions that are experienced by the family members are evident in our findings. This contributes to their experience of chaos as the unexpected nature of their experience may potentially preclude resolution of the transitions. Also, the chaos experience in this study is not only related to roles, but also to the experience of caregiving of a person who is dying.
As the study participants were actively caregiving at the time of this study, their stories of chaos and hope are ongoing. Understanding the chaos of hope and caregiving is important, as Frank (1995) suggests:

Getting out of chaos is to be desired, but people can only be helped out when those who care are first willing to be witnesses to the story. Chaos is never transcended but must be accepted before new lives can be built and new stories told. Those who care for lives emerging from chaos have to accept that chaos always remains the story’s background and will continually face into the foreground. (1995: 110)

It is our hope that by illustrating the caregivers’ stories of chaos and hope through poetic transcription that the poem ‘The Chaos of Caregiving and Hope’ may bring meaning to their caregiving experience.

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