

Elderly palliative care cancer patients' descriptions of hope-fostering strategies

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Abstract

The purpose of this study was to describe perceptions of hope-fostering strategies of elderly patients with advanced cancer receiving palliative home care. Using a qualitative thematic research design, saturation was reached with 10 palliative home care patients (mean age 75 years) (five males and five females). Face-to-face audiotaped interviews were conducted in the participants' homes. Participants described hope for: 'not suffering more', 'living life to the fullest in the little time I have left', a peaceful death, life after death and 'hope for a better life in the future' for their family. Using Lubrosky's thematic analysis, themes of fostering their hope were: leaving a legacy, achieving short-term goals, 'turn your mind off', supportive family and friends, symbols of hope, positive thoughts, honest information and symptom control.

Over 200 000 people die in Canada each year, the majority of whom are 65 years of age and older (Carstairs and Beaudoin, 2000). Approximately one quarter of these deaths are from advanced cancer. Those with advanced cancer experience a spectrum of symptoms, such as pain, which are often untreated and interfere with quality of life (Donnelly and Walsh, 1995; Phillips et al, 2000). Elderly palliative care cancer patients describe their worst pain as psychosocial pain, defined as loss of independence, of life, faith and relationships (Duggleby, 2000a). They deal with this pain and suffering by maintaining hope (Duggleby, 2000b). Hope is an inner resource, a process and coping mechanism essential for elderly palliative care patients' quality of life (Duggleby, 2001).

Very little is known about what fosters hope in elderly palliative care patients. This study was the first phase in the development of a psychosocial hope intervention for older palliative care cancer patients. The purpose was to describe perceptions of strategies that foster hope of elderly palliative care patients with advanced cancer. The specific aims were to describe the

experience of hope in older palliative home care patients with cancer, and to describe the strategies that foster their hope.

Background

Several studies have reported the importance of hope for palliative care patients (Hall, 1990; Herth, 1990; Perakyla, 1991; Flemming, 1997; Greisinger et al, 1997; Duggleby, 2000b; Benzien et al, 2001). As with other populations, hope in palliative care patients has been associated with positive outcomes, such as coping with pain and terminal illness (Hall, 1990; Herth, 1990; Perakyla, 1991).

Palliative care patients define their hope as hope for: positive future of living day by day (Hall, 1990), feeling better (Perakyla, 1991), relief of pain (Duggleby, 2000b), a peaceful death (Greisinger et al, 1997), life after death (Duggleby 2000b) and happy future for their families (Herth, 1990). Other populations, such as medical surgical patients, focus their hope on 'getting better' and 'living longer' (Perakyla, 1991). Palliative care patients experience a tension between hope for a cure and reconciliation with life and death (Benzien et al, 2001). Because of the different focus of hope in palliative care patients, ways of fostering hope may differ from other populations.

Two studies have reported hope-fostering strategies used by palliative care nurses (Cutcliffe, 1995; Herth, 1995). It is not clear, however, if these strategies were effective. *Table 1* outlines four studies that reported palliative/hospice patients' perspectives on what fostered or hindered their hope. Common ways to foster hope were: good symptom control, achieving short-term goals, supportive relationships, faith, acceptance/or reconciliation to life situations and a positive outlook. One study described the importance of information (Benzien et al, 2001), another described light-heartedness, personal

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attributes and affirmation of worth as a person (Herth, 1990). Differences in study findings may be the result of different study purposes, types of palliative/hospice patients studied and methods. The studies also included a wide variety of ages. Older adults (65 years and older) may need different methods of maintaining and fostering hope than younger persons (Farran et al, 1990; Herth, 1993) because elderly cancer patients cope with their cancer experience by integrating it into 'a life mostly lived' (Kagan, 1997). With only four studies reporting findings related to ways of fostering/hindering hope in palliative/hospice patients and no reported studies focusing on older adults, very little is known about older palliative care patients' perceptions of ways to foster hope.

Method

A qualitative thematic research design was used to address the specific aims of identifying and describing older palliative home care cancer patients' perceptions of strategies that foster hope.

Procedures

The study was approved by an institutional review board. The research assistant was an experienced home care registered nurse who received training about how to obtain an informed consent and collect data for the study.

The interviews took place in the participant's homes, located in rural Canadian prairie communities. The palliative care coordinator identified potential subjects based on the inclusion criteria and determined their willingness to talk with a researcher about the study. The palliative care coordinator notified the research assistant, who then contacted potential participants by telephone and met them in their homes to explain the study and obtain written informed consent. All participants who were approached agreed to participate. Following completion of the data collection instruments described below, participants were interviewed.

Data collection instruments

Herth Hope Index (HHI)

The HHI, a 12-item (1-4 point) Likert scale, was used as a demographic measure to describe the participants' levels of hope in this study. The HHI has been found to be a reliable and valid measure of hope in terminally ill patients (Herth, 1992). Summative scores on the HHI can range from 12-48, with a higher score denoting greater hope.

Edmonton Symptom Assessment Scale (ESAS)

The ESAS allows for rapid assessment and interpretation of nine symptoms: pain, activity, nausea, depression, anxiety,

Table 1. Research studies reporting ways of fostering hope in palliative care patients

Authors	Purpose	Sample	Method	Findings: ways of fostering/hindering hope
Benzien et al (2001)	Meaning of the lived experience of hope	n=11, cancer palliative home care age: 54-83 years (median 65) Sweden	Phenomenology	Good symptom control, summary of life, achieving short-term goals, supportive relationships, faith, acceptance/or reconciliation to life situations, information
Fleming (1997)	Meaning of the hope experience	n=4, cancer two inpatient two visiting centres age: 40-88 years (mean not reported) UK	Content analysis	Religious faith, retrospective analysis on life, control over existing circumstances
Hall (1990)	Explore the concept of hope	n=11 terminally ill HIV/AIDS patients age not reported USA	Not reported	Affect-control strategies, achieving short-term goals, positive outlook, supportive relationships
Herth (1990)	Meaning of hope and identify ways to foster hope	n=30 hospice home care age: 24-88 years (mean 51 years) USA	Content analysis	Hope fostering: interpersonal/ connectedness, light-heartedness, personal attainable aims, spirituality, uplifting memories, affirmation of worth. Hope hindering: abandonment and isolation, uncontrollable pain, devaluation of personhood

drowsiness, appetite, wellbeing and shortness of breath (Chang et al, 2000). The patient chooses between 0 (none) and 10 (severe) to describe the symptoms he/she is experiencing. It was used in this study as a demographic measure to describe the sample.

Demographic form

Information such as age, occupation (current or past), ethnicity, religious affiliation, other conditions, education levels, medical diagnosis, medications and time of admission to palliative care was collected by interviewing the participant and from the medical record using a demographic form.

Sample

Using theoretical purposive sampling, saturation was reached by interviewing 10 participants. The participants were chosen one at a time, following interview and analysis of data from the preceding participant. Sampling continued until saturation was reached, i.e. until there was repetition and no new data were obtained. Theoretical sampling and saturation are methods of ensuring the sample is appropriate and adequate (Marcus and Liehr, 1998).

Inclusion criteria for the study were:

- Male or female 65 years and over
- Diagnosed with cancer
- Receiving palliative home care services from a rural Canadian health region
- English speaking
- An overall PPS score of 30% or above
- A Palliative Performance Scale (PPS) score of 60% or above for conscious level
- Consent to participate.

The PPS was used to ensure that participants were able, cognitively and physically, to take part in the study. It has been found to be a reliable and valid tool for functional performance and progressive decline in palliative care patients (Anderson et al, 1996; Virik and Glare, 2002). It also has a screening tool for confusion, a score below 60% indicating confusion.

Five participants were female and five male. The mean age of the participants was 75 years (range 65–85 years). All participants were Caucasian and diagnosed with various types of cancer, as well as secondary conditions such as kidney disease, arthritis, and heart conditions. The average number of years in education was 10.7 years (range 8–16 years). Total HHI scores were high (mean 42.70/48, range 34–48) and total Edmonton Symptom Assessment Scale (ESAS) scores were low (mean 2.21). *Table 2* presents participants' demographic characteristics.

Sixteen interviews were completed. Whenever possible the participants were interviewed twice to allow them to review their transcripts for accuracy and to clarify interpretations of the data. Four participants were unable to be re-interviewed because of physical symptoms (*n*=3) or death (*n*=1).

Interviews

Participants were interviewed using broad open-ended questions, followed by questions adapted to the individual in order to clarify individual responses. The questions were adapted from Herth (1990) and included: 'Tell me about hope', 'What gives you hope?', 'What kinds of things change (increase or decrease) your hope?' and 'What can nurses do to help you have hope?'. Interviews ranged from 15–60 minutes in duration. All interviews were audiotaped. Written field notes were also made regarding the setting, nonverbal behaviours and participants' interactions with other people, such as family members, and the environment.

Data analysis

Qualitative data were stored and managed using the Nonnumerical Unstructured Data Indexing, Searching and Theorizing (NUD*IST) software. All the data were analysed using Lubrosky's (1994) thematic analysis methodology. Discourse analysis techniques were used to identify the main points and topics, which had the most meaning to participants. From the main

Table 2. Demographic characteristics of participants, *n*=10

Characteristics		Number	Percentage
Marital status:	Married	7	70%
	Widowed	3	30%
	Single	0	0
	Divorced	0	0
Religious preference:	Protestant	8	80%
	Catholic	2	20%
	No preference:	0	0
Household residents:	Alone	3	30%
	With spouse	7	70%
Primary caregivers:	Spouses	7	70%
	Daughter	1	10%
	Son	1	10%
	None	1	10%

'The participants described leaving a legacy as an important way to engender their hope.'

points and topics, themes emerged that best illustrated the data. Field notes were used to assist in interpretation of the data.

Credibility, auditability, fittingness and confirmability, as defined by Marcus and Liehr (1998), were established throughout the study by the following steps: all audiotaped individual interviews and field notes were transcribed verbatim; the transcripts were reviewed and corrected by listening to the audiotapes; emerging themes used the participant's language; and the co-investigator and principal investigator analysed the transcripts separately throughout the study, then met to discuss emerging themes and resolved differences in analysis. Raw data, field notes and memos were kept, providing an audit trail.

Results

Participants described hope as important, dynamic and a choice. As one participant said:

*'You can't live without hope'.
(Participant 1)*

Another participant said:

*'I guess if you don't have any hope, I would say you just slowly wither away. I would almost think. If you don't have any hope, then you have nothing for the future or even for the present.'
(Participant 4)*

Participants also described how their hope had changed from when they were younger and with the knowledge that their illness was advanced:

*'well, to a dying man, hope has a different meaning than a 35-year-old man just starting a family'
(Participant 3)*

They described their hope for 'not suffering more', 'living life to the fullest in the little time I have left', peaceful death, life after death and 'hope for a better life in the future' for their family. As well as being important and dynamic, hope was a choice, an important one as:

*'Most of us are going to have a tough time with the rest of our lives and our direction is down that last tough road of life and it's going to continue to be tough. What you can do is you can make it tougher in your mind or you can make it easier in your mind.'
(Participant 5)*

Fostering hope

Participants identified several hope-fostering strategies. Themes focused on: leaving a legacy, achieving short-term goals, 'turn your mind off', supportive family and friends, symbols of hope, positive thoughts, honest information from health-care professionals and symptom control. Data examples of these themes are illustrated in *Table 3*.

Leaving a legacy

The participants described leaving a legacy as an important way to engender their hope. Legacy was defined as 'leaving something behind' of value to others. This included writing letters to grandchildren to read in the future, past contributions in their careers, participating in this research study, sharing lessons in life with their families, preparing their spouses for their death and past acts of kindness to others. Leaving a legacy gave meaning to their lives:

*'Right now, what gives my life meaning? My life has meaning to the people that I've assisted in growing up, in getting them a start in life.'
(Participant 5)*

Participants described a legacy as living on even when they are no longer alive:

*'... it contributes to your hope to know that those will live on...'
(Participant 7)*

Achieving short-term goals

Hope was fostered through achieving short-term goals, which gave meaning and value to participants' lives. These short-term goals ranged from baking muffins, to getting through the day with minimal shortness of breath, to arranging for their funerals. Setting and achieving short-term goals helped participants to live 'one day at a time'. Succeeding, achieving or accomplishing a short-term goal gave participants feelings of control in a situation where they often did not have control. Losing control hindered their hope:

*'that diminishes your hope a little bit because you have to lose control.'
(Participant 5)*

By giving the participants a feeling of control, the achievement of short-term goals contributed to a feeling of hope, and added to the meaning of their life.

'Turn your mind off'

'Turn your mind off' by keeping busy, doing puzzles, hobbies and leisure activities, and humour helped participants deal with uncontrolled symptoms and the uncertainty of 'never knowing what is ahead of us'. For example, keeping busy was important so they did not have to continuously focus on what was happening to them and maintain relationships with others. As one participant said:

'... you hope to get by by keeping yourself busy and not becoming a pain in the rump for a whole bunch of people.'

(Participant 3)

'Turn your mind off' helped to foster hope, because the participants did not constantly focus on the negative aspects of what was happening to them:

'I kind of think... when I am in trouble I

try to turn my mind off of it and I try to think well, it's only going to last awhile.'

(Participant 2)

Supportive family and friends

Support and encouragement from family and friends also fostered hope for the participants. Family and friends fostered hope by 'smiles' and by caring. Families were considered part of the participants' legacy:

'Hope is in your family too... Things they accomplish'

(Participant 5)

Families' accomplishments were viewed as the participants' accomplishments adding value and meaning to their life.

Faith

Participants identified faith a source of strength, trust, and hope:

Table 3. Data examples for hope-fostering strategies

Hope-fostering strategy	Example
Leaving a legacy	'You've got to think of what you are leaving behind' (Participant 3) '... what you have accomplished. I think it helps us in life, at least to keep hope.' (Participant 4) 'And I think a lot of us feel that's why they were put upon this earth was to make a difference in other people's lives' (Participant 5)
Short-term goals	'Everyday, try to accomplish what... even if you don't today... you've got to have a goal in something' (Participant 3) 'Well I really achieved something, I made some muffins the other day for us, and I haven't baked for months.' (Participant 7) 'As far as long-term goals, you really don't have many because you can start something today and tomorrow something will come along and you can't do that.' (Participant 5)
'turn your mind off'	'I usually block that from my mind' (Participant 9) '... a little bit of humor in there somewhere to kind of get your mind off what...' (Participant 3)
Supportive family and friends	'I do have a few very, very close friends who I talk to them about that [participant's illness] and it helps. And I know that it's between us.' (Participant 6) 'It's amazing sometimes the love that somebody will give you and it's maybe not much, like a card of some kind, or a little pin, it means so much. It just gives you a lift. Somebody really cares and I think caring and love that goes hand in hand.' (Participant 9)
Faith	'I have faith that gives me comfort' (Participant 6) 'My views anyway on God, certainly mean hope to me.' (Participant 5) 'He has assured me that He will look after me in my times of trouble.' (Participant 10)
Symbols of hope	'These robins they hop along and they sing to me, they say, "cheer up, cheer up"' (Participant 10)
Positive thoughts	'Well there's possibilities, you've gotta think positive.' (Participant 9)
Honest information from health-care professionals	'and she [named nurse] said, "You know [participants name], this [chemotherapy] is killing you. It's not helping you." And I said, "Thank you very much, because I was feeling that myself"' (Participant 2)
Controlling symptoms	'When I'm in dire need of pain relief. I just give up.' (Participant 6)

'Participants described the importance of having positive thoughts to help them refocus their hope.'

'God has instilled hope for us...'
(Participant 4)

Hope was a gift from God and participants trusted God to care of them and take away their suffering. Faith also fostered hope through helping participants make sense of what was happening to them:

'I think without God I don't have any hope at all. He certainly does provide a spot, or a garden for our thoughts.'
(Participant 5)

Symbols of hope

Symbols of hope for the participants focused on nature images such as gardens, birds, animals and colours. For example green was a colour that represented hope for one participant:

'well green is everything about hope and that's why I pick it.'
(Participant 10)

The symbols seemed to remind participants that things can change for the better giving them hope for the future:

'... nice and green it looks, it seems to bring something out to you that in such a short time God can just switch things around.'
(Participant 4)

Positive thoughts

Participants described the importance of having positive thoughts to help them refocus their hope. As one participant said:

'I've had to change my outlook on that now, I'll find something else to do, and when that happens I guess that's the way you change your hope'
(Participant 5)

Negative outlook hindered their hope:

'If you're negative about everything in this world. You don't have much going for you.'
(Participant 5)

Honest information

Health-care professionals played an important role in fostering or hindering the participants' hope. Participants described how honest information from nurses and doctors helped them to refocus their hope:

'... his [doctor's] job is to inform you and I've always said, if there's something

wrong with me, you tell me and [doctor] did exactly that when he found out what I had.'

(Participant 6)

Another participant described how communication between her and her doctor that was not honest hindered her hope:

'... don't come in here and lie to me because it's not going to work... If you are going to lie to me about that [terminal illness], whereabouts are you going to stop?'
(Participant 5)

Controlling symptoms

Participants described controlling symptoms, such as pain, depression, nausea, constipation, loss of appetite, shortness of breath and weight loss, fostered their hope. Uncontrolled symptoms hindered their hope:

'if you feel really in pain and down in the dumps, it's pretty hard to think about how far you're going to go.'
(Participant 3)

Although uncontrolled symptoms diminished their hope, participants described how hope could not be taken away, that it was always there, just difficult to find sometimes:

'Actually, I kept it [hope]. I think it was always there.'
(Participant 2)

Discussion

Although it is difficult to compare the results of this study with others because of differences in purposes and methods, there are some shared findings. Similarities with other studies of hope in palliative care patients included the importance and dynamic nature of hope (Herth, 1990; Greisinger et al, 1997). Other similarities were the focus of hope for not suffering more, for living life to the fullest, a peaceful death, life after death and for the future of their families (Hall, 1990; Herth, 1990; Perakyla, 1991; Duggleby, 2000a; Benzien et al, 2001). Differing from other studies were the participant's descriptions of having hope as a choice, although it is implied in Benzien et al's (2001) study referring to the 'will' of palliative care patients to live with hope. More research is needed to determine if hope as a choice is found in other populations as well.

'Using symbols of hope may be an effective way to foster hope in older palliative care patients.'

Fostering hope

Similar findings to other studies reporting ways to foster hope in palliative care patients (*Table 1*) included the role of supportive relationships, positive outlook, faith, symptom control, honest information and achieving short-term goals. Unique to this study were the themes of leaving a legacy, 'turn your mind off' and symbols of hope.

Legacy

Finding meaning was described as a concept in several studies of hope in palliative care patients (Hall, 1990; Herth, 1990; Flemming, 1997; Duggleby, 2000b; Benzien et al, 2001) The participants in this study, however, described an additional aspect to finding meaning in life, as the importance of legacy, of leaving something of value behind.

Thomas and Retsas (1999) suggested in the results of their study of spirituality with palliative care patients that the patients over 71 years described having already accomplished something as important to them, whereas the patients under 71 did not. Benzien, et al (2000), in their study of healthy adults (aged 18–80 years), described one aspect of hope as 'being related to the world', which included the concept of legacy. Because of the wide range of age groups in their study and different purpose to this study, it is unclear whether 'leaving a legacy' is a hope-fostering strategy for all age groups or unique to older adults. It does appear, however, that leaving a legacy is an important way of fostering hope in palliative care patients.

'Turn your mind off'

Another difference between the results of this study and other hope studies was the theme 'turn your mind off'. 'Turn your mind off', by using distraction techniques, has been used successfully by older palliative care patients in the management of pain (Duggleby, 2000a). Kagan (1997) also described this theme as part of the way older cancer patients integrated their illness experience into a life mostly lived. As well, in a study of decision-making in palliative care patients, the participants described the importance of forgetting their bodies to whatever degree possible in order to reconnect with the world (Bottorff et al, 1998). 'Turn your mind off' was important for fostering hope by enabling palliative care

patients to focus on important relationships with others. More research is needed, however, to determine if this strategy is used by younger palliative care patients as well.

Symbols of hope

Identifying and focusing on symbols of hope have been incorporated into hope interventions (Herth, 2000, 2001). The symbols of hope described by the participants in this study were focused on nature. Sensory impressions of nature have been described as essential for wellbeing (Benzien et al, 2000). Using symbols of hope may be an effective way to foster hope in older palliative care patients.

Limitations


There are several limitations to this study related to the sample and method. The sample was 10 palliative home care patients living in a rural Canadian region. Palliative home care patients in different geographic regions, of different ethnicity, other religious or non-religious preferences, lower education levels and incomes may describe their hope and ways their hope is fostered differently.

The participants also reported high hope levels and low symptom levels. The HHI mean scores were higher than those found in other samples of terminally ill patients (Herth, 1992). However, in Herth's (1992) study the mean age of the terminally ill participants was 51 years and there are no reported studies that have used the HHI focusing specifically on elderly palliative patients. More research is needed with participants with lower hope scores and higher symptom levels. This, however, may be difficult, as palliative care patients with uncontrolled symptoms are often unable to participate in research.

Although the qualitative method was essential to explore the perceptions of the participants as ways to foster their hope, future research should also explore which strategies caregivers and health-care professionals can effectively use to foster palliative care patients' hope. Research should be conducted to include participants of other ethnic backgrounds, religious preferences, age groups, diseases and geographic areas.

Conclusion

Although there are limitations to this study, the findings contribute to further understanding the ways older palliative

care cancer patients foster their hope. The findings also provide a foundation for the development of effective hope-fostering strategies in this population. Developing effective ways to foster hope will assist health-care professionals and patients' families help palliative care patients live with hope, and die with dignity, peace and comfort. 

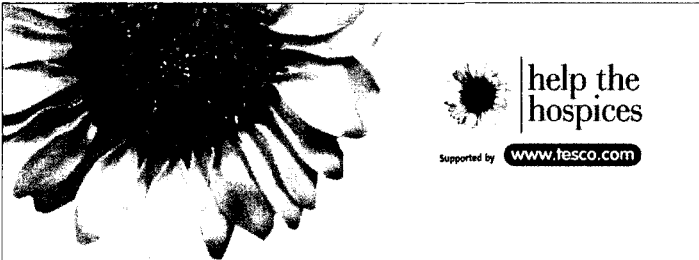
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