Palliative and Supportive Care (2011), **9**, 43–54.
© Cambridge University Press, 2011 1478-9515/11 $20.00
doi:10.1017/S1478951510000532

The glimmering embers: Experiences of hope among cancer patients in palliative home care

LOUISE OLSSON, R.N.T., PH.D.,[1] GUNNEL ÖSTLUND, PH.D.,[1] PETER STRANG, M.D., PH.D.,[2] EVA JEPPSSON GRASSMAN, PH.D.,[1] AND MARIA FRIEDRICHSEN, S.R.N., PH.D.[1,3]

[1]Department of Social and Welfare Studies, Faculty of Health Sciences, Campus Norrköping, Linköping University, Norrköping, Sweden
[2]Karolinska Institutet, FoUU, Stockholms sjukhem, Mariebergsgatan, Stockholm, Sweden
[3]Palliative Education and Research Center Unit of Palliative Care, Vrinnevi Hospital, Norrköping, Sweden

(RECEIVED February 14, 2010; ACCEPTED April 23, 2010)

ABSTRACT

Objective: The experience of hope among cancer patients in palliative care is important information for healthcare providers, but research on the subject is sparse. The aim of this article was to explore how cancer patients admitted to palliative home care experienced the significance of hope and used hope during 6 weeks throughout the last phase of their life, and to assess their symptoms and hope status during 6 weeks throughout the last phase of their lives.

Method: Eleven adult patients with cancer participated in 20 interviews and completed seven diaries. The participants were recruited from two palliative care units in the southeast of Sweden. The method used was Grounded Theory (GT), and analysis was based on the constant comparative method.

Results: The core category, glimmering embers, was generated from four processes: (1) The creation of "convinced" hope, with a focus on positive events, formed in order to have something to look forward to; (2) The creation of "simulated hope," including awareness of the lack of realism, but including attempts to believe in unrealistic reasons for hope; (3) The collection of and maintaining of moments of hope, expressing a wish to "seize the day" and hold on to moments of joy and pleasure; and (4) "Gradually extinct" hope, characterized by a lack of energy and a sense of time running out.

Significance of results: The different processes of hope helped the patients to continue to live when they were close to death. Hope should be respected and understood by the professionals giving them support.

KEYWORDS: Hope, Meaning, GT, Cancer, Palliative care

INTRODUCTION

Approximately, 23,000 adults with cancer die each year in Sweden (Socialstyrelsen, 2008). Lung cancer is now the most common cause of cancer deaths among women, and prostate cancer is the most common cause of cancer deaths among men (Socialstyrelsen, 2007).

Palliative care is the active, total care of patients whose disease does not respond to curative treatment (World Health Organization, 2008). Control of symptoms, and of social, psychological, and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and affirms life, whereas dying is seen as a normal process. The focus is on preserving the best possible quality of life until death, which incorporates existential needs, of which hope is one aspect (MacLeod & Carter, 1999; Chochinov & Cann, 2005). In Sweden there are 139 care units that follow the WHO definition of palliative care. The units are organized differently: oncology units, palliative home care units, hospices, primary care teams, geriatric units, and pediatric units. All are free of charge. When a Swedish cancer patient

---

Address correspondence and reprint requests to: Louise Olsson, Department of Social and Welfare Studies, Faculty of Health Sciences, Linköping University, Campus Norrköping, SE 601 74 Norrköping, Sweden. E-mail: louol@isv.liu.se

does not respond to tumor-specific treatment he/she is offered a referral to a palliative care team.

The transition from curative to palliative care is one of the most complicated existential challenges according to patients, as well as to families and healthcare professionals. This is also a time in the process when hope can be influenced (Friedrichsen et al., 2000; Baile & Aaron, 2005; Tulsky, 2005b; Friedrichsen & Milberg, 2006). A relationship built on trust between team members and patients is a key factor in order to communicate hope (Tulsky, 2005a, 2005b). Healthcare professionals often associate hope with cure and life (MacLeod & Carter, 1999) and failure/hopelessness with death. Terminally ill patients conveyed a hopeful attitude by stating that hope was explained as both "to hope for something" and to "be in hope" (Benzein et al., 2001).

In psychology, the construct of hope has been described in terms of goal attainment (Stotland, 1969; Snyder et al., 2006). Psychological theories are very useful, but in palliative care it is important to extend the view of hope beyond the (one-dimensional) framework of future long-term goal setting and problem solving. The patients are not always able to focus on future goals because of their lack of time or strength. Several definitions of hope have evolved in nursing research. Farran et al. (1992) described a "Hope Process Framework" where four central attributes of hope were presented. These universal attributes include an experiential, a spiritual, a rational thought, and a relational process.

Perspectives about hope have mainly been examined in three different populations in palliative care, cancer, elderly, and HIV/AIDS. Patients with HIV/AIDS defined hope as having faith in future possibilities (Kylmä & Vehvilainen-Julkunen, 1997). However, for dying HIV/AIDS patients and cancer patients the future might be perceived as frightening and threatening. When the illness is progressing, treatment will change and will become extremely important for these groups of patients (Kylmä & Vehvilainen-Julkunen, 1997; Kirk et al., 2004).

Quantitative studies of psychosocial hope interventions for the elderly living at home in the end-of-life phase have also been conducted. These interventions consisted of watching a video about hope and hope-generating activities (Duggleby et al., 2007). In a qualitative study the core category was entitled "transformation of hope," which was facilitated by the control of symptoms, spirituality, and supportive relationships (Duggleby & Wright, 2005). Nursing researchers have criticized quantitative hope studies for not capturing the human experience (Kim et al., 2006). A tenet of Parse (1999) is that hope is a universal human experience arising in a setting of personal uniqueness. She argues that the concept of hope should be understood and supported rather than being assessed or measured, or becoming the subject of intervention (Parse, 1999).

Some qualitative studies have focused on the meaning of hope (Fleming, 1997; Benzein et al., 2001) and elucidated how terminally ill individuals maintain and kindle their hope (Salander et al., 1996; Nekolaichuk & Bruera, 1998, 2004). However, research has not been focused on patients' perspectives of hope from an early palliative phase to the transition to the late palliative phase in the home care setting. Patients in palliative care are not only from one advanced age group (Duggleby & Wright, 2004) or one cancer diagnosis (Salander et al., 1996) but can be children, teenagers, and the middle-aged.

A hope model for palliative care presented by Nekolaichuk & Bruera (1998), comprises three dimensions and views the experience of hope as an integration taking place involving the personal spirit, a personal dimension; the risk, a situational dimension; and authentic caring, an interpersonal dimension. This hope model on spiritual/existential factors captures the inner process of hope. Even developed research models need to expand the knowledge base, explore and support the development of the understanding of hope, and place the individual's hope in the context of the disease process (Back et al., 2003; Nekolaichuk & Bruera, 2004) and the dying process (Nekolaichuk & Bruera, 1998; Hirari et al., 2006). Their is a need for further research with the aim of capturing the intangible inner experiences of hope (Herth & Cutcliffe, 2002; Nekolaichuk & Bruera, 2004).

The aim of this article was threefold: (1) to explore how cancer patients admitted to palliative home care experienced the significance of hope; (2) how cancer patients used hope; and (3) to assess their symptoms and hope status during 6 weeks throughout the last phase of their lives.

METHOD

Grounded theory (GT) has its roots in symbolic interactionism (Blumer, 1973; Strauss & Corbin, 1998). Most important in this approach is the meaning individuals give to events and the symbols that convey this meaning. By collecting subjective experiences of a phenomenon, the researcher attempts to identify psychosocial processes. A constant comparative method is used and the theoretical interpretations are developed continuously in the research process by moving back and forth between the empirical material and the researcher's interpretations. GT is multi-methodological, using both qualitative and quantitative data. This study was approved by the Regional Research Ethical Board at Linköping University.

Setting and Sampling

The study was performed in two palliative care units in two different counties in the southeast of Sweden. The setting was an advanced, palliative, hospital-based home care setting, organized according to the Swedish Motala model. The Swedish Motala model includes physicians, nurses, auxiliary staff, occupational therapists, physiotherapists, and social workers (Beck-Friis & Strang, 1993). Physicians and nurses are available 24 hours a day and the care is free of charge. A back-up hospital ward is available when needed, for example when home care is failing, such as when patients perceive break-through pain.

The following inclusion criteria were used:

- being an adult patient with a cancer diagnosis in a palliative state living at home
- being admitted to palliative home-care or having received a palliative care consultation
- having the physical and psychological capacity to participate according to the patient's own judgement
- being able to speak, read, and write in Swedish
- accepting being tape-recorded.

A purposive sampling technique was used in order to reflect diversity related to age, gender, occupation, diagnosis, religious beliefs, time since diagnosis, etc. A demographic form designed for the study was constructed.

Data Collections

In GT several methods for data collection can be used, such as observations, interviews, documents, biographies, or videotapes (Strauss & Corbin, 1998). The purpose of using interviews in GT in this study was to explore the participants' own experiences of hope. A total of 11 participants were interviewed once and 9 of them were interviewed twice. Two participants could not be re-interviewed because of physical symptoms ($n = 1$) or death ($n = 1$). A total of 20 interviews were conducted. Out of 11 participants, 7 also wrote diaries. Four participants were not able to write diaries because of fatigue ($n = 3$) or language-related issues ($n = 1$). Data analysis was integrated with data collection. The sample size was not predetermined, but ended when data were saturated, in the open coding process when the preliminary categories emerged (Strauss & Corbin, 1998).

The data collection methods used were interviews, diaries, and questionnaires (as presented in Table 1) intended to follow the patients' experiences and use of hope. Tape-recorded open-ended interviews were repeated twice; one at the start of the study and again after 6 weeks. An interview guide was initially constructed focusing on the meaning of hope and how it influenced daily life (Patton, 2002) for example "What does hope mean to you?" "Tell me about a situation when your hope was affected?" The participants' were additionally asked to write diaries concerning feelings of hope and if hope changed. These questions were inspired by Nekolaichuk and Bruera (1998) but were just an aid to start writing, and not mandatory. When conducting the second interview the questions were based on the analysis from the first interview and the diary. One of the co-investigators conducted all the interviews, 19 in the participants' homes and 1 in the palliative care unit. The data collection was performed during the period 2005–2007. The time for each one of the interviews varied between 30 and 90 minutes, with the mean being about 75 minutes. The interviews and diaries were transcribed verbatim by the interviewer or a secretary.

Herth Hope Index- Sweden

Participants in the study approved tools that were used to measure hope and symptom burden at baseline, after 3 weeks and at the time of the final interview after an additional 3 weeks. This was done in order to describe the studied group more intensely and was seen as a complementary to the qualitative data .The Herth Hope Index (HHI) was chosen because it is based on a multi-dimensional concept of hope, is fitting in clinical settings, and is brief. Time for completing the Herth Hope Index- Sweden (HHI-S) was about 7 minutes. Hope was measured using the Swedish version of the HHI, which is a shortened version of the Herth Hope Scale (HHS) (Herth, 1992). This scale is conceptualized from the model of hope by Dufault and Martocchio (1985). HHI is a 12-item (1–4 points) Likert scale that

Table 1. *The research design for quantitative and qualitative data collection*

Baseline	Week 1–5	Week 6
Interview 1	Diary	Interview 2
Instrument HHI-S	HHI-S (3 times)	HHI-S
Instrument ESAS	ESAS (3 times)	ESAS

delineates three factors of hope; inner sense of temporality and future; inner positive readiness; and expectancy and interconnectedness with self and others. Summative scores range from 12 to 48, with a higher score denoting greater hope. HHI has been translated and validated for a Swedish population in palliative care and is called HHI-S (Benzein & Berg, 2003) and has previously been used in palliative home care.

Edmonton Symptom Assessment Scale

Symptoms were rated according to the Edmonton Symptom Assessment Scale (ESAS) (Bruera et al., 1991). ESAS is a short scale, used in palliative care and translated into the Nordic languages (Richardson & Jones, 2009). The literature provides no theoretical justification for the ESAS and its content. Instead, the goal of the ESAS is practical: to identify a few active symptoms using a consistent listing and scoring system across patients (Richardson & Jones, 2009). The Swedish version of ESAS (Heedman & Strang, 2003) consists of a nine visual analog scale (VAS) (0–10) used for assessments of pain, activity, nausea, depression, anxiety, drowsiness, appetite, sensation of well-being, and dyspnea. Low values, irrespective of the scale, represent good function.

Data Analysis

Data such as verbal interviews, diaries, and code notes were analyzed using the constant comparative method (Strauss & Corbin, 1998). Open, axial, and selective coding were used, which resulted in increasing levels of interpretation of the analysis. The open text coding included examining each interview, breaking the transcript down into individual units of meaning, and labeling the units to identify the categories and concepts. Following text coding was axial coding, where we specified the relationship between categories. These substantive codes were grouped into categories by investigating and vertically and horizontally comparing different data sections and codes, in an attempt to conceptualize and categorize every part of the text (Glaser & Strauss, 1967; Strauss & Corbin, 1998). In the axial coding we asked questions such as: “what does hope mean,” “what or who gives hope/despair,” “what are the consequences of hope or hopelessness for whom and why.” We were looking for reasons, problems, consequences, strategies, and interactions/actions in between concepts, codes, and categories.

The last step of the coding was selective coding. This step included one core category. The core category is identified when a category or a variable occurs frequently and seems to link other categories together (Schreiber & Stern, 2001). In this study that category was “The Glimmering Embers of Hope.” The core category is central in data and forms the theoretical model together with the other categories and the so-called story line. Relationships between the categories, as well as the basic psychosocial process, were established (Strauss & Corbin, 1998). Theoretical sensitivity was used to determine how data emerged and to determine every step of the analysis with the goal of developing a model grounded in empirical data (Glaser & Strauss, 1967; Strauss & Corbin, 1998). Memos were used during the analyzing process to act as reflections of analytical thought and to create the model. The quantitative data were calculated by descriptive statistics.

Ensuring Rigor in GT

In this study there were researchers from different fields such as nursing, sociology, and medicine, i.e. investigator triangulation (Patton, 2002). The coding process was conducted between three researchers in different steps. During the coding process, the common problems were also validated through discussion in seminars with Ph.D. students as well as in a palliative research group. Continued written memos and notes from the field were taken to help validity (Jeon, 2004) We have also used different data collection methods to validate the congruence of the same phenomenon across points in time (Kimchi et al., 1991).

RESULTS

Eleven cancer patients admitted to palliative home care with varying characteristics were recruited (as presented in Table 2). The results of the HHI- S and ESAS scores can be seen (as presented in Tables 3 and 4). The total score of HHI-S was during the three measurements: 36,37 and 34,90, indicating moderate-to-high levels of hope. Low scores were found in item three “I feel alone” and higher scores in item “I believe that each day has potential” after 3 weeks. No other changes in hope status were seen over these 6 weeks. The results in respective dimensions were:

> the inner sense of temporality and future 12,32; 12,41; and 11,60
>
> the inner positive readiness and expectancy: 13,05; 13,41; and 12,50 and
>
> interconnectedness with self and others: 11,31; 10,55, and 10,80

In the results measurements we could not find obvious changes in hope, as patients themselves

Table 2. *The characteristics of the 11 patients*

Demographic data	No. of participants
Number	11
Gender	
Female	5
Male	6
Median age (range)	58 (59)
Occupation (*n*)	
Old-age pensioner	5
Living on sickness benefit	1
Childminder	2
Medical Doctor's Secretary	1
Student	1
Police	1
Status (*n*)	
Married or cohabiting	9
Living in a relationship	1
Divorced	1
Primary cancer site	
Gastrointestinal	4
Melanoma	1
Breast	2
Gynecological/Prostate	2
Lung	2
Religion	
Christian	3
Non-Christian, but belief in Higher Being	1
No religious belief	7
Time between first interview and death	
<1 month	1
1–3 months	4
3–6 months	2
6–12 months	1
>1 year	2
>2 year	1

described hope moving between the different sub-processes.

The ESAS showed that pain decreased a lot. Activity was found to be high after 3 weeks but decreased in measure 3. The total score was 29,83; 30,61; and 25,25. Low scores were found in total symptom assessment.

The Glimmering Embers of Hope

In this study "the glimmering embers" was the core category and four sub-processes emerged from data. The glimmering embers of hope mean an inner sanctum present in every person's life. Four different sub-processes of hope circulating around this core category emerged from data. The first sub-process, the creation of convinced hope, is focused on positive opportunities, and patients striving to have something to look forward to. The second sub-process, the creation of simulated hope, is when patients want to believe in hope even if they know it is unrealistic. The third sub-process, the collection and maintaining of moments of hope, implies desires to continue to "seize the day" and hold on to moments of joy and pleasure. Lastly the fourth sub-process, the gradually extinct hope, is when patients lack energy and have a sense of time running out. Hope changes over time, depending upon health, general well-being, and the social situation. From the patients' experiences a model

Table 3. *HHI-S measured three times during 6 weeks*

Items in respective dimension	HHI-S 1 *n* = 9	HHI-S 2 *n* = 7	HHI-S 3 *n* = 5
Inner sense of temporality and future.			
I have short /long range goals	3,22	3,28	2,60
I have a positive outlook toward life	3,22	3,28	3,00
I believe that each day has potential	3,26	3,57	3,60
I feel scared about my life	2,62	2,28	2,40
Inner positive readiness and expectancy			
I can see a light in the tunnel	2,85	3,28	2,50
I have a sense of direction	2,88	2,71	2,60
I feel my life has a value	3,66	3,71	3,60
I can recall happy/joyful times	3,66	3,71	3,80
Interconnectedness with self and others			
I feel all alone	1,33	1,00	1,40
I have faith that gives me comfort	2,77	2,42	2,40
I have a deep inner strength	3,55	3,42	3,20
I am able to give and receive caring and love	3,66	3,71	3,80
Total score	36,68	36,37	34,90

Table 4. *ESAS measured three times during 6 weeks*

	ESAS 1 *n* = 9	ESAS 2 *n* = 7	ESAS 3 *n* = 5
Pain	3,61	5,05	1,52
Fatigue	4,32	6,05	3,46
Nausea	1,10	1,91	1,12
Depression	3,34	2,65	2,00
Anxiety	3,27	1,82	2,60
Drowsiness	2,95	2,95	3,88
Appetite	2,15	2,08	1,25
Well-being	3,01	3,05	3,80
Dyspnoea	2,73	2,15	2,72
QoL	3,35	2,90	2,90
Total score	29,83	30,61	25,25

was developed in which hope in a palliative care setting was described as a process.

"The glimmering embers of hope" was the core category. During the interviews, some of the participants described hope as a glimmer or a glow present from birth onwards, something that always exists, that everyone needs all the time and that is continuous. Hope and life were strongly intertwined and expressed as "without hope there is no life." Hope was a companion, a fellow traveler. It belonged to the individual and could not be taken away by any other person or event; it can just be influenced. Hope was seen as one of the human qualities every person is entitled to have constant access to throughout life. Supporting hope should therefore be respected by the nurses and the healthcare provider, as it is essential in, and fundamental for, human life. The loss of this glow would therefore mean the loss of the very meaning in life. The following quotes illustrate the patients' views on the glimmering embers of hope.

> The children will arrive home and it is a great help, it kindles the flame. I feel well – I should be able to go on a bit longer, no matter what the doctors say. (Interview 2.1, man with pancreatic cancer)
>
> What would life be without hope – just meaningless. (Interview 3.1, woman with lung cancer)

Having access to basic hope contributed to a feeling of freedom and independence, an expression of the right to think and the ability to do what you want. Even if the disease was progressing, the patients still experienced that they had the right and the possibility to hope in different ways and to believe in positive things and events happening to them.

The Creation of Convinced Hope

The first sub-process involved the patients describing their experience of the creation of convinced hope. The patients focused on positive events and opportunities for the future. For example, patients described possible medical or alternative treatments, forthcoming holidays, and things they looked forward to. Some patients even explicitly believed in a miracle and had thoughts that formed a hope of recovery. A general sense of well-being greatly influenced the experience of convinced hope even if the patient's health was deteriorating. Every opportunity to have additional time in life created hope among the patients, but at the same time they accepted the new situation. Patients tried to convince themselves and others that there really was hope. They were eager to influence their medical condition by using their courage and to fight against the illness. Through this strategy they tried to buy extra time in life. Convinced hope also gave the patients something in return; the positive thoughts made them feel better subjectively and increased their inner strength and motivation to keep fighting for life. Through creating convinced hope they consciously made active choices to have faith in the future. The following quote illustrates the patients' perspectives.

> I can't rule out the fact that I will recover and respond well to the treatment, it is a part of my hope and I am prepared to fight. (Interview 8.2, man with gastrointestinal cancer)

Despite medical staff giving the patients information about their prognosis, the patients actively chose to ignore their disease's progress or would not let anyone (even the physicians) take away their hope. Instead they created their own hope. Patients were well aware that no one with any certainty can predict when a person is going to die. Most of the interviewees had a strong sense of duty; they felt they had to get on with life; if not for themselves then for their children or other people they had close relationships with. By keeping their convinced hope strong the patients also managed to avoid questions and discussions about the uncertain future.

> I had a chat with a doctor there. She is always talking along these lines. She wants to steer the conversation towards death. I asked her to stop. I don't think about death since I actually still have got hope. (Diary 6, woman with gastrointestinal cancer)
>
> I still have my own hope and whatever the doctors tell me, that fact will not change. . . and I think I am the one who knows my body better than anyone else, I really think that is the case. (Interview 10.2, woman with gynecological cancer)
>
> And then I know that when the cancer relapses, it's often even more aggressive. I do have hope and it helps and I am entitled to hold on to it. (Interview 10.1, woman with gynecological cancer)

The patients did not reflect a lot on death. Nothing was definite, yet they were convinced they would get well again. At this point, their own death was still a far-off concept rather than a reality. Yet they were in a palliative context.

The Creation of Simulated Hope

The second sub-process was that the patients described their attempts to grasp hope by the creation of simulated hope. Hope was created when the patients no longer were completely convinced that there was any real hope. The patients still attempted to hope for a cure, even if they knew it was unrealistic and out of reach. They wanted to safeguard themselves from disappointment. Their modest belief or active thoughts made the days easier to get through. The patients experienced a certain amount of vague hope even if they could not fully believe in it when they used logical reasoning. The majority of the patients indicated that they had the courage to hope, but thought that it might not be correct or safe to truly believe in it. The following quotes illustrates the patients' perspectives.

> I sensed there was a possibility, although I knew it would be highly improbable with my logical reasoning, that I would be one of the lucky few able to pull through. The answer (from his physician) came back, and I did not have the slow growing type of cancer. So the opportunity to pick trumps with a slow growing cancer was not to be mine. Instead, something that was exactly what gave me even more hope was the response to a direct question about how rapidly the existing cancer cells would develop, I got the answer that the speed of that process was impossible to ascertain. (Diary 2, man with pancreatic cancer)

The patients used several different external sources to create hope; hopeful, positive persons around them, physicians, and "positive" laboratory results. A hopeful person nearby would perceive the patient's situation, and be able to encourage and stimulate the patient's hope. The communication with the physician could also encourage the feeling of hope, i.e. an unspecific answer created the opportunity for the patient's fantasy of a possible future and this fantasy was used to stimulate hope. Professionals who gave this kind of support were perceived to be able to provide joy and hope. If the patients experienced an increased number of difficult symptoms but simultaneously received news about some test results being normal, they would sometimes interpret this as "a good message," which increased their hope. Furthermore, some of the interviewees said that they were inspired by an alternative therapist from whom they felt they got support. Most of the interviewees claimed that it was better to hold on to a grain of hope than to have no hope at all.

> Every sick person needs another person to get hope from if they can't manage to create it by themselves. (Interview 6.1, woman with gastrointestinal cancer)

> I don't believe in healing but at least it gives some hope. (Interview 6.1, woman with gastrointestinal cancer)

> It makes me hope that it's no longer active and that nothing more will happen. It‘s certainly odd and the doctor himself is wondering what's going on. It gave me the strongest hope I have experienced so far. (Interview 1.1, man with melanoma cancer, talking about his conversation with his doctor)

The Collection of and Maintaining Moments of Hope

The third sub-process involved the patients describing their attempt to collect and maintain moments of hope. Some patients focused on small things and events in their everyday life, such as enjoying relationships, hobbies, or sharing a nice meal with someone. They tried to maintain moments of hope. Collecting meaningful moments was important for them and created space for rest, reflection, and hope in a situation when their existence was under serious threat. The patients described how they actively chose things they really wanted to do, because they knew that tomorrow was unknown. These patients did not have enough hope to hope for a longer life. However, some patients described that they still had hope, but only as fragments. These patients were aware of the knowledge of their life being limited but they still had a wish to "seize the day" and cling on to moments of joy and pleasure. The patients interviewed said they wished they could stop time during these intense moments. By valuing close relationships and "seizing the day" they almost felt they managed to do this. The following quotes illustrates one patient's transition from being worried about the future to become comfortable with the situation here and now, hoping for the good moments.

> Hopefulness, the hope that maybe I can be like this for another three or four month.
>
> The difficult part is when everyone else is planning for Christmas and springtime, for instance reading flower bulb catalogues, and I don't know if I'll be alive in spring. I just want to "seize the day," hold on to every moment and get it to last for as long as possible. (Interview 2.1, man with pancreatic cancer)
>
> We are enjoying life. . .experiencing another dimension. I notice that my mind is calm, and it is not only due to the pills. I know my time is limited, so I'm not postponing anything, we're trying to do whatever we want straight away. (Interview 2.2, man with pancreatic cancer)

Gradually Extinct Hope

In the last sub-process patients described the perception that hope was fading away. These patients had tried to create hope, but were aware that there was not much left to build their hopes on. When hope faded away, their energy simultaneously ebbed away. Some of the patients interviewed felt that they were in a situation where they no longer had any influence over their life situation. This could be the result of a specific incident, a general lack of energy, or a clear sense of time running out. The patients wished they were able to have hopeful thoughts about the future, but felt that they had lost most of their courage and ability to do so. Some patients talked about this as a slow disappearance of hope. The individual would still be able to continue living for an hour, a day, or even a week but would just be waiting for death. The following quotes illustrate the patients' perspectives.

> In spite of all the help, it's not enough, I feel insignificant, and I can't even describe it. (Interview 3.1, woman with lung cancer)
>
> Psychologically, I am broken, now and forever. I firmly believed I had a strong character but I don't. I was under the impression I was able to cope with almost anything, but I can't. (Interview 3.2, woman with lung cancer)

Some patients with gradually extinct hope feared that they would "tip over" into death, i.e. lose all hope. When the patients no longer could influence their situation, they found it extremely difficult to live with their symptoms. The patients also knew that if they had no hope or meaning left in life it would mean that they had given up and therefore they would die very quickly. The following illustrates the patients' perspectives.

> A lot of people die within a few months if they lose hope. (Interview 6.1, woman with gastrointestinal cancer)
>
> When I think about last week I haven't found anything positive about my illness, on the contrary it's just worse. (Diary 7, man with gastrointestinal cancer)

Hope fades away when the patient no longer has enough psychological and physical energy to live. Some of the patients who experienced that their hope was ebbing away from them were very close to death, whereas others just had received bad news about their prognosis. These patients felt they were losing all hope and would be forced to literally spend the rest of their lives waiting to die. Some patients completely lost all their strength and the ability to care about anything that happened around them or to themselves. Patients described how they had lost any meaning and any reason to stay alive. The following quotes illustrate the patients' perspectives.

> The news was like an ice-cold shower, and I immediately felt a strong sense of hopelessness. . .it's horrible, awful. But maybe this is a rare cancer form which doesn't progress very quickly. The chance might be microscopically small, but even if it's microscopic, it still exists. (Interview 2, man with pancreatic cancer)

A Model of Hope in Palliative Care

The glimmering embers of hope in their different manifestations can be understood as a single process in which the embers represent the core, an inner glowing part with four different sub-processes circulating around this inner nucleus. These sub-processes did not start or end in chronological order or develop step-by-step. Instead, patients would often move between the different sub-processes. The nucleus is represented by the glimmering embers; always present despite adverse circumstances and even if death is imminent. A faint glimmer or glow can be transformed by a spark to a flame or fire and might change from one moment to the next, depending upon different circumstances such as bad or good news, symptom progression or relief, treatment options, and support functions. Patients could receive a bad prognosis and move from "convinced hope" (strongly glowing embers in a fire) to "gradually extinct hope" (only a fading, extremely faint glow). After a while some patients might move back to "convinced hope" and so on. Others felt too overwhelmed by symptoms and stayed in "moments of hope," but could undergo a transition to "convinced hope" after symptom management (as presented in Figure 1). Despite feeling physically well, some patients experienced that hope was fading, and at the other end of the spectrum patients who were in bad physical shape could experience convinced hope.

DISCUSSION

In this study, adult patients with cancer described their perspective on hope while receiving palliative care. We found that patients were able to move between the different sub-processes. But all of them had an inner core, a glow, which was always present but not perceptible or visible to other people. This inner core was described and interpreted in terms of being a fundamental human characteristic closely linked to dignity and equality. To a certain extent this explains why hope is so important, as it is related to a person's free choice, a person's inner space.

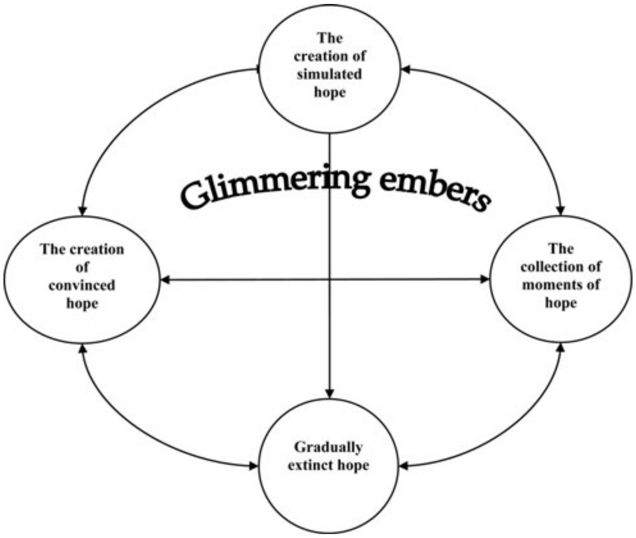

Fig. 1. Model of the process of hope among patients in palliative care.

A meta-analysis of various studies on hope in different contexts posited that hope is a subjective phenomenon and a dynamic process (Kylmä & Vehvilainen-Julkunen, 1997). Still, debate exists over whether hope can be described as a continuum between hope and hopelessness. We would suggest, based on our results, that hope can be described as a transition from one reference point to another and that the reference points vary over time, depending upon factors such as health and well-being, social situation, and context. Patients may move among different sub-processes of hope. Dying patients' coping strategies can be described (Sand et al., 2008) as a pendulum between factors, such as, hope as life and resignation as death. The coping strategies served the purpose of counterbalancing death with symbolic manifestations of life (Sand et al., 2008). Our results found all processes of hope to be symbolic of life although they might be so, to different degrees, until death occurs. This transition between various processes of hope gives time and creates meaning for the patient, instead of meaninglessness. Patients have several manifestations of hope to choose from, which can give them a sense of creating more time in life. It is possible for a patient to fall directly from convinced hope to gradually extinct hope, or to the worst sub-process, which is being completely beyond hope, i.e. total meaninglessness and hopelessness.

The results of the present study have indicated that the patients' experiences in a single hope process varied. In convinced hope, for example, one patient could focus on a wish to recover, whereas another patient would have a wish not to die just yet. This could be dependent upon where the patient was in the trajectory. The different sub-processes of hope in the palliative phase might be graded according to intensity and strength, both in comparison with each other in order to distinguish among them, but also within each of the four sub-processes of hope. The highest grade of intensity was found in convinced hope followed by simulated hope (illustrated in our model Figure 1); when experiencing moments of hope, the faint glimmer or glow would momentarily grow and become a flame. When hope was gradually extinct there was still a faint glow even though the patient could not find a future goal to believe in.

In line with the current study's results, Nekolaichuk and Bruera (1998) as well as Duggleby and Wright (2005), have shown that the construction of meaning was important for patientś hope. The meaning is described as a sub-process of transforming hope by Duggleby and Wright (2005) whereas others put the emphasis on existential factors, where meaning is just one aspect (Nekolaichuk & Bruera, 1998).

The findings in this study illustrate factors in the environment that can contribute to hope and offer "an injection of hope" to patients, which will increase their motivation to keep hoping. Patients who experienced the "simulated hope" sub-process were in need of more support from their surrounding environment than were patients in the other hope processes. Support for hope included manifestations of belief in the patients as courageous and strong individuals but could also consist of pure symptom management.

LIMITATIONS

There are several limitations to this study. In GT a theoretical sample should be used. This study's sampling of patients was more based on purposeful sampling. We had to include all the patients we were able to find. Hope might be a delicate and highly personal topic and patients who chose to participate in this study were generally courageous and believed in their own ability. The study therefore runs the risk of excluding patients who did not have access to the same strength. This influences credibility negatively but is mitigated by the fact that some patients were able to go on participating even while their disease was progressing. In the second interview or when writing diaries, they clearly did not have the same strength as in the previous interview.

This is a limited amount of material, but patients in this phase of life might find it easier to participate in an interview rather than to answer questionnaires. This could be linked to cognitive fatigue which can result in reading problems. However, this is not shown in the measurements in this study where the levels of hope did not change while fatigue and well-being as well as drowsiness increased (as presented in Tables 3 and 4), which could be the result of treatment with corticosteroids (Lundström & Furst, 2006). A replication of this study is possible but not easy to do, as this group of patients is vulnerable. They are close to death and their physical, psychological, and existential status might change rapidly. The patients' own experiences of the measurement ESAS described (Watanabe et al., 2009). They thought that ESAS had difficult terminology, but the measurement was easy to complete with a healthcare professional present. Patients expressed a need to emphasize the timeframe as "now."

The authors in this study have different professional backgrounds, which is perceived as a method of achieving confirmability. We were surprised that our professional backgrounds did not influence the analysis more than they did. This could be a strength, as we judged the material in a similar way, and it was assessed from many perspectives. Still, we agreed upon the main results. Yet there could also be a weakness, as the analysis might be too premature and superficial.

Further research could focus more on the hopelessness near death, and if it is possible to describe a similar process of hopelessness. Another important aspect would be to explore how hope is communicated in hospices, hospitals, or home care settings by patients, families and different groups of professionals.

IMPLICATIONS

Some patients in this study described hope as a miracle. Fantasies and magical thinking near death have also been described by Sand et al. (2008) who claimed that they represented important metaphors, steps on the way in a step-by-step acceptance of the thought of non-existence. It is a likely explanation that it becomes meaningless for patients to think about death at the end of life. The future, even the future beyond death, is therefore perceived as a reality. This does not, paradoxically, mean that the patients believe in an existence after death. Patients who were committed to creating and protecting an illusion of hope was described (Salander et al., 1996). The illusion was like a companion of protection and hope that kept the real threat away. This could represent a reality, truth, and hope through the creation of an illusion and could explain patients' sense of well-being even though they were dying. This knowledge is of great importance for clinicians. Dying patients must have something to hope for, even though the healthy people around them might find it incomprehensible that they can.

Professionals might potentially fear the rapid transitions. To avoid too rapid and negative movements and to help patients, we suggest it might be useful to carefully plan all interventions, in particular the communication of bad news (Morita et al., 2004; Baile & Aaron, 2005; Tulsky, 2005 a, 2005b). Efforts aimed at positively influencing hope can help patients to use their energy in connection with other challenges in the palliative phase. When there are strong reminders about death in a patient's life, a few minutes of hope become an important symbol of life. This can be interpreted as false hope, but it is a way for patients to survive psychologically. It is important for healthcare professionals to show respect for patients and their hope, and to be sensitive and understand the process of death for the dying patient. For patients and their families, networks and personal relationships seemed to be an important social capital at the end of life (Jeppsson Grassman & Whitaker, 2007).

The current study has explored the many facets of hope, which change over time as something that can give patients the meaning needed to be able to get on with life despite a life-threatening illness. The findings in this study point to the inner experiences of hope that we have described in our proposed hope model, which needs further testing. We followed the patients' experiences of hope over a period of 6 weeks. This has given us an opportunity to see how hope changed over time, but that the single identified core category of hope was always present, despite different circumstances. The result of this study might be transferable to other similar settings, such as in the care for older people living at home.

CONCLUSIONS

To conclude, the study has revealed that hope can be described as glimmering embers with sub-processes. The patients were shown to have a need of these different processes of hope, as they helped the patients to survive close to death. Hope was a symbol for life in a dying patient. It is a paradoxical and complicated balancing act for the patients, which should be respected and understood by the professionals giving them support.

REFERENCES

Back, A.L., Arnold, R.M. & Quill, T.E. (2003). Hope for the best but prepare for the worst. *Annals of Internal Medicine*, *138*, 439–443.

Baile, W.F. & Aaron, J. (2005). Patient-physician communication in oncology: Past, present and future. *Current Opinion in Oncology*, *17*, 331–335.

Beck-Friis, B. & Strang, P. (1993). The organization of hospital-based home care for terminally ill cancer patients. The Motala model. *Palliative Medicine*, *7*, 93–100.

Benzein, E. & Berg, A. (2003). The Swedish version of Herth Hope Index - an instrument for palliative care. *Scandinavian Journal Caring Sciences*, *17*, 409–415.

Benzien, E., Norberg, A. & Saveman, B.-I. (2001). Meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliative Medicine*, *15*, 117–226.

Blumer, H. (1973). A note on symbolic interactionism. *American Sociological Review*, *38*, 797–798.

Bruera, E., Kuehn, N., Miller, M., et al. (1991). The Edmonton Symptom Assessment System(ESAS): a simple method for the assessment of palliative care patients. *Journal of Palliative Care*, *7*, 6–9.

Chochinov, H.M. & Cann, B.J. (2005). Interventions to enhance the spiritual aspects of dying. *Journal of Palliative Medicine*, *8*, 103–115.

Dufault, K. & Martocchio, B.C. (1985). Hope: It's spheres and dimensions. *Nursing Clinics of North America*, *20*, 379–391.

Duggleby, W. & Wright, K. (2004). Elderly palliative care cancer patients descriptions of hope-fostering strategies. *International Journal of Palliative Nursing*, *10*, 352–359.

Duggleby, W.D., Degner, L., Williams, A., et al. (2007). Living with hope: Initial evaluation of a psychosocial hope intervention for older palliative home care patients. *Journal of Pain and Symptom Management*, *33*, 247–257.

Duggleby, W.D. & Wright, K. (2005). Transforming Hope: How elderly palliative patients live with hope. *Clinical Journal of Nursing Research*, *37*, 70–84.

Farran, C.J., Wiken, C.S. & Popovich, J. M. (1992). Clinical assessment of hope. *Issues in Mental Health*, *13*, 129–138.

Fleming, K. (1997). The meaning of hope to palliative cancer patients. *International Journal of Palliative Nursing*, *3*, 14–18.

Friedrichsen, M. & Milberg, A. (2006). Concerns about losing control when breaking bad news to terminally ill patients with cancer: Physicians' perspective. *Journal of Palliative Medicine*, *9*, 673–682.

Friedrichsen, M., Strang, P. & Carlsson, M. (2000). Breaking bad news in the transition from curative to palliative cancer care-patients view of the doctor giving the information. *Supportive Care in Cancer*, *8*, 472–478.

Glaser, B.G. & Strauss, A.L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: Aldine de Gruyter.

Heedman, P.A. & Strang, P. (2003). Pain and pain alleviation in hospital-based home care; demographic, biological and treatment factors. *Support Cancer Care*, *11*, 35–40.

Herth, K. (1992). Abbreviated instrument to measure hope: Development and psychometric evaluation. *Journal of Advanced Nursing*, *17*, 1251–1259.

Herth, K.A. & Cutcliffe, J.R. (2002). The concept of hope in nursing 3: Hope and palliative care nursing. *British Journal of Nursing*, *11*, 977–983.

Hirari, K., Miyashita, M., Morita, T., et al. (2006). Good death in Japanese cancer care: A qualitative study. *Journal of Pain and Symptom Management*, *31*, 140–147.

Jeon, Y.-H. (2004). The application of grounded theory and symbolic interactionism. *Scandinavian Journal of Caring Sciences*, *18*, 249–256.

Jeppsson Grassman, E. & Whitaker, A. (2007). End of life and dimensions of civil society: The church of Sweden in a new geography of death. *Mortality*, *12*, 261–280.

Kim, D.S., Kim, D.S., Schwartz-Barcott, D., et al. (2006). The nature of hope in hospitalized chronically ill patients. *International Journal of Nursing Studies*, *43*, 547–556.

Kimchi, J., Polivka, B. & Stevenson, J.S. (1991). Triangulation: Operational definitions. *Nursing Research*, *40*, 364–366.

Kirk, P., Kirk, I. & Kristjanson, L.J. (2004). What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *British Medical Journal*, *328*, 1343–1349.

Kylmä, J. & Vehvilainen-Julkunen, K. (1997). Hope in nursing research: A meta-analysis of the ontological and epistemological foundations of hope. *Journal of Advanced Nursing*, *25*, 346–371.

Lundström, S.H. & Furst, C.J. (2006). The use of corticosteroids in Swedish palliative care. *Acta Oncologica*, *45*, 430–437.

MacLeod, R. & Carter, H. (1999). Health professional's perception of hope: Understanding its significance in the care of people who are dying. *Mortality*, *4*, 309–318.

Morita, T., Akechi, T., Ikenaga, M., et al. (2004). Communication about the ending of anticancer treatment and transition to palliative care. *Annals of Oncology*, *15*, 1551–1557.

Nekolaichuk, C.L. & Bruera, E. (1998). On the nature of hope in palliative care. *Journal of palliative care*, *14*, 36–42.

Nekolaichuk, C.L. & Bruera, E. (2004). Assessing hope at the end of life: validation of an experience of hope scale in advanced cancer patients. *Palliative and Supportive Care*, *2*, 243–253.

Parse, R.R. (1999). *Hope: An International Human Becoming Perspective*. Sudbury: Jones & Bartlett.

Patton, M.Q. (2002). *Qualitative Research and Evaluation Methods, 3rd Ed*. Thousands Oaks: Sage Publications Inc.

Richardson, L.A. & Jones, G.W. (2009). A review of the reliability and validity of the Edmonton Symptom Assessment System. *Current Oncology*, *16*, 53–64.

Salander, P., Bergenheim, T. & Henriksson, R. (1996). The creation of protection and hope in patients with malignant brain tumours. *Social Science Medicine*, *42*, 985–996.

Sand, L., Strang, P. & Milberg, A. (2008). Dying patients' experiences of powerlessness and helplessness. *Journal of Supportive Care in Cancer*, *16*, 853–862.

Schreiber, R.S. & Stern, P.N. (2001). *Using Grounded Theory in Nursing*. New York: Springer.

Snyder, C.R., Lehman, K.A., Kluck, B., et al. (2006). Hope for rehabilitation and vice versa. *Rehabilitation Psychology*, *51*, 89–112.

Socialstyrelsen (2007). *Causes of Death*. The National Board of Health and Welfare. 2009.

Socialstyrelsen (2008). Dödsorsaker 2006. *Statistik, hälsa och sjukdomar 2008:6*.

Stotland, E. (1969). *The Psychology of Hope: An Integration of Experimental, Clinical and Social Approaches*. San Francisco: Jossey-Bass.

Strauss, A. & Corbin, J. (1998). *Basics of Qualitative Research. Techniques and Procedures for Developing Grounded Theory*. London: Sage.

Tulsky, J. (2005a). Beyond advanced directives: importance of communication skills at the end of life. *Journal of the American Medical Association*, *294*, 359–365.

Tulsky, J.A. (2005b). Interventions to enhance communication among patients, providers and families. *Journal of Palliative Medicine*, *8*, 95–102.

Watanabe, S., Nekolaichuk, C., Beaumont, C., et al. (2009). The Edmonton Symptom Assessment System - what do patients think? *Support Care Cancer*, *17*, 675–683.

World Health Originaziation. (2008). WHO Definition of Palliative Care. http://www.who.int/cancer/palliative/definition/en/.