Résumé

Transformer l'espoir :
L'espoir chez les personnes âgées
en soins palliatifs

Wendy Duggleby et Karen Wright

L'espoir est important pour les patients en soins palliatifs; toutefois, le processus qui permet à ces patients de continuer à vivre et à espérer est inconnu. Cette étude théorique à base empirique décrit les processus qui permettent aux patients en soins palliatifs de continuer à espérer. Seize entrevues ont été menées auprès de 10 patients recevant des soins palliatifs à domicile (moyenne d'âge 75 ans) auxquels on a posé des questions ouvertes. Les participants définissent l'espoir comme les attentes qu'ils ont, par exemple, de ne pas souffrir d'avantage et de mourir paisiblement. Ils décrivent leur principale préoccupation comme étant de vouloir « vivre et continuer à espérer » et ils y arrivent grâce au processus social fondamental de la transformation de l'espoir, ce qui implique d'accepter la « vie comme elle est », chercher du sens et procéder à une réévaluation positive. Les résultats de cette étude serviront de fondement à des recherches futures et à l'élaboration d'interventions visant à susciter l'espoir chez les patients âgés en soins palliatifs.

Mots clés: soins palliatifs, personnes âgées, espoir

Transforming Hope:
How Elderly Palliative Patients
Live With Hope

Wendy Duggleby and Karen Wright

Hope is important to palliative patients; however, the process by which these patients live with hope is unknown. The purpose of this study was to describe, using a grounded theory approach, the processes by which palliative patients live with hope. Sixteen interviews were conducted with 10 home-care palliative patients (mean age 75 years) in their homes using open-ended questions. The participants defined their hope as expectations such as not suffering more and having a peaceful death. They described their main concern as wanting to "live with hope" and they achieved this through the basic social process of transforming hope. Transforming hope involved acknowledging "life the way it is," searching for meaning, and positive reappraisal. The results of this study provide a foundation for future research and the development of interventions to engender hope in older palliative patients.

Keywords: palliative, elderly, hope, qualitative research

Introduction

The alleviation of suffering at the end of life is considered a realistic goal for all health-care professionals (Lindholm & Erickson, 1993). Palliative patients describe their suffering in terms of multiple physical, psychological, and social losses (Daneault et al., 2004). They describe hope as the ability to endure and cope with their suffering (Duggleby, 2000). For patients with incurable cancer, hope is important for a meaningful life and a peaceful death (Benzein, Norberg, & Saveman, 2001).

Several studies of hope in palliative care patients have found that it is very important to these individuals (Benzein et al., 2001; Buckley & Herth, 2004; Duggleby, 2000; Duggleby & Wright, 2004; Hall, 1990; Herth, 1990). However, we do not know how palliative patients maintain their hope in the context of multiple losses. A grounded theory qualitative approach to uncovering the processes by which older palliative care patients maintain their hope may lead to the development of strategies for fostering hope in this population. By increasing hope we may be able to contribute to patients' quality of life (Herth, 2000), which is a goal of end–of–life care (Carstairs & Beaudoin, 2002).

The purpose of this study was to describe the processes by which older palliative home-care patients with advanced cancer live with hope. Specific strategies used by the participants to foster the hope identified in this study are described elsewhere (Duggleby & Wright, 2004).

Background

Although several studies have been conducted on hope in patients with cancer and chronic diseases, very few have focused on the hope experience of terminally ill patients (Duggleby, 2001). Two studies examined nurses' perceptions of how they fostered hope in palliative patients (Cutcliffe, 1995; Herth, 1995), though it is unknown whether their perceived means of fostering hope were actually effective. Another study examined nurses' perceptions of the hope experience of palliative cancer patients (Benzein et al., 2001; Benzein & Saveman, 1998). Nurses' views of the patients' hope experience may not be accurate, however, as health-care professionals often view the hope of terminally ill patients as a form of denial or false reality (Perakyla, 1991).

Interviews conducted with palliative patients suggest that they define hope as an inner resource and as a coping mechanism essential for their quality of life (Benzein et al., 2001; Buckley & Herth, 2004; Flemming, 1997; Hall, 1990; Herth, 1990). The patients hoped for the avoidance of suffering, a peaceful death, and life after death. Some patients also hoped for a better life for their families. The focus of hope in palliative patients is different from that in other patient populations. Medical/surgical patients (Cameron, 1993; Perakyla, 1991), stroke patients (Bays, 2001), and patients with chronic pain (Howell, 1994) focus their hope on getting better and living longer. The fact that palliative patients define hope differently suggests that their processes of hope may also differ from those of other patient populations.

Research examining the focus of hope for palliative patients has identified strategies that foster hope for these individuals. Such strategies include good symptom control, the setting of short-term goals, faith/spirituality, positive outlook, and connectedness. However, it is not known when and how patients use these strategies. Moreover, the methodological approaches used to examine hope in the studies conducted so far have not allowed for the description of the processes associated with hope. These limitations suggest the need for exploratory research into the processes of hope in the palliative population, in order to facilitate the development of theoretically based frameworks for future hope interventions.

Methods

A qualitative, grounded theory approach (Glaser, 1992, 2001) was used to identify the processes of the hope experience for older palliative home-care patients with advanced cancer. The greatest contribution of grounded theory is in areas in which little research has been done and few adequate theories exist to explain or predict a group's behaviour (Chenitz & Swanson, 1986). It is "a very useful method to understand what is going on in a substantive area and how to explain and interpret it" (Glaser, 1978, p. 3). Specific interventions are more likely to emerge from the data when grounded theory is used as a methodological approach to studying hope (Cutcliffe & Grant, 2001).

Procedure

The study was approved by an Institutional Ethical Review Board. The palliative care coordinator in the health region identified potential participants based on the following criteria: male or female over the age of 65; diagnosed with cancer; receiving palliative home-care services from a rural Canadian health region; English-speaking; Palliative Performance Scale score of at least 30% overall; PPS score of at least 60% for consciousness level; and consent to participate. The PPS was used as a screening tool in order to exclude those who were unable to physically or cognitively participate. It is a reliable and valid measure of functional performance, progressive decline, and confusion in palliative patients (Virik & Glare, 2002).

When potential participants agreed to take part in the study, the research assistant contacted them to describe the study and arrange to meet them in their homes at their convenience. The research assistant (RN–RA) was an experienced palliative home-care nurse trained in obtaining consent and in data collection. At the first visit before data collection, the RN–RA obtained written informed consent.

Data collection entailed a demographic form, face-to-face individual interviews, and information from the patient's chart. The participants also completed the Herth Hope Index (HHI) and the Edmonton Symptom Assessment Scale (ESAS) to describe levels of hope and symptom intensity, respectively. The HHI has been found to be a reliable measure of hope in terminally ill patients (Herth, 1992). It consists of a 12-item, four-point Likert scale with a summative score; higher summative scores denote greater hope. The ESAS consists of nine reliable and valid numerical rating scales of symptom intensity (Chang, Hwang, & Feureman, 2000); higher scores denote greater intensity.

Open-ended audiotaped interviews ranging from 15 to 60 minutes in duration were conducted in the homes of the participants. Questions were asked that invited participants to: describe hope, identify the things that gave them hope, specify the things that increased or decreased hope, and describe what others could do to foster hope.

In addition, field notes were taken on the setting, the non-verbal behaviours of participants, and the interactions of participants with others such as family members and with the environment.

Data Analysis

Each interview was transcribed verbatim. The transcription was then checked for accuracy by the RN-RA who had conducted the interview. Consistent with grounded theory methods, data analysis was carried out concurrently with data collection. Interview data were examined line by line using the constant comparative approach of grounded theory. From the transcripts, codes were identified using the participant's language as much as possible. Then the codes were grouped together to identify processes and underlying patterns. Coding occurred at three levels using Glaser's (2001) approach: open, selective, and theoretical. Open coding was completed when the main concern and basic social process were identified. Selective coding was focused on the basic social process and sub-processes. In theoretical coding, the relationships between substantive codes were conceptualized. The researchers used selective sampling of the literature throughout the analysis to help them fill in the missing pieces in the emerging theory. They used memoing to preserve ideas that came up throughout the data analysis with regard to the emerging theory.

Scientific rigour in qualitative research is judged on the basis of credibility, auditability, fittingness, and confirmability (Marcus & Liehr, 1998). In this study the audiotapes were transcribed verbatim and the participant's language was used in coding, categorizing, and theory writing to establish credibility. Credibility of the findings was also established by confirming the results with the participants whenever possible. Auditability was achieved by keeping raw data, field notes, and memos, ensuring an audit trail. Fittingness of the data was ensured by grounding theoretical observations in the data, and through cross coding and categorization of data. As well, the principal investigator and the co-investigator independently coded selected transcripts throughout the study and then compared the results.

Results

Sample

Ten participants were interviewed in their homes, located in a rural prairie community in Canada. Purposive sampling was used to select par-

ticipants of different genders, various ages, and with different types of cancer. Unsuccessful attempts were made to recruit patients who had low hope scores and high symptom scores. Once data analysis revealed the basic social process (BSP) present in the data, theoretical sampling was used to select interviewees who would inform the facets and dimensions of the BSP.

Five (50%) of the participants were female and five (50%) male. The age of the participants ranged from 65 to 85 years with a mean age of 75 years. All participants were Caucasian and had been diagnosed with various types of cancer as well as secondary conditions such as kidney disease, arthritis, or heart conditions. The average number of years of education was 10.70 (range: 8–16 years). The majority of participants were married (70%; 30% widowed) and lived with their spouse (70%; 30% lived alone). All participants identified a religious preference, with 80% being Protestant and 20% Catholic. Mean HHI scores were 42.7/48 (range: 34–48), indicating high levels of hope, and ESAS scores were low (mean: 2.21), indicating minimal levels of symptom intensity.

Whenever possible, participants were interviewed twice, in order to have them review their transcript and to explore the concepts highlighted in the first interview. A total of 16 interviews were completed. Six participants reviewed their transcript. Four could not be re-interviewed because of physical symptoms ($n = 3$) or death ($n = 1$).

Main Concern: Living With Hope

From the analysis of transcribed interview data a main concern and a core category were identified. Glaser (2001) describes the main concern as the main preoccupation of the participants. In the present study, participants described their main concern as wishing to "live with hope" in spite of multiple losses with respect to function, independence, relationships, goals, and a longer life. The participants said it was important for them to "live life," "keep on going," and "live day by day." When asked what happens if one does not have hope, one 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." Another said: "You can't live without hope."

Core Category: Transforming Hope

In grounded theory, the main concern is continually resolved through a core category, which "organizes and explains most of the variation in how the main concern is resolved" (Glaser, 2001, p. 199). In order to live with hope, the participants described the basic social process of transforming hope. Hope was dynamic: "Well, it changes, that's for sure." The

participants had made a conscious decision to change or transform their hope: "What you can do is you can make it tougher in your mind or you can make it easier in your mind."

Through the process of transforming hope, new patterns of hope emerged. These were apparent in the participants' ways of defining hope as a future expectation — "something you hope will happen." They defined their future in terms of minutes, hours, and days and also in terms of their families. For example, they described their hope in terms of "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. This differed from their previous patterns of hope, which for some participants included being cured of cancer, living longer, and achieving long-term goals.

The process of transforming hope was facilitated by controlled symptoms, supportive relationships, and spirituality. For example, the participants said that uncontrolled symptoms made it difficult for them to think about the future: "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." Supportive relationships were those in which friends and family members provided comfort and hope: "It's comfort from friends, from relatives, and the hope they are giving me." Spirituality fostered hope by providing a framework for understanding what was happening to them and a source of strength in terms of hope: "I think without God I don't have any hope at all. He certainly does provide a spot, or a garden, for our thoughts."

The participants described the sub-processes of transforming hope as acknowledging "life the way it is," searching for meaning, and positive reappraisal. Figure 1 illustrates the basic social process of transforming hope and its sub-processes. Although the figure appears to be linear, the processes are dynamic and interrelated.

Acknowledging "Life the Way It Is"

The participants began the process of transforming hope by acknowledging the changes that had occurred in their lives. Acknowledging "life the way it is" is the recognition that previous expectations and hopes are no longer viable. Two ways of acknowledging "life the way it is" were seeking information and recognizing the shift from what was to what is. One participant expressed the importance of seeking information: "If you don't know the good and the bad, or the pros and the cons, how can you decide on anything?" In this regard, the participants appreciated receiving honest information from nurses and doctors.

In order to accept the change from what was to what is, the participants had to come to terms with their losses, to acknowledge the impracticality of making holiday travel plans, for example, or the fact that they

Figure 1   *Transforming Hope*
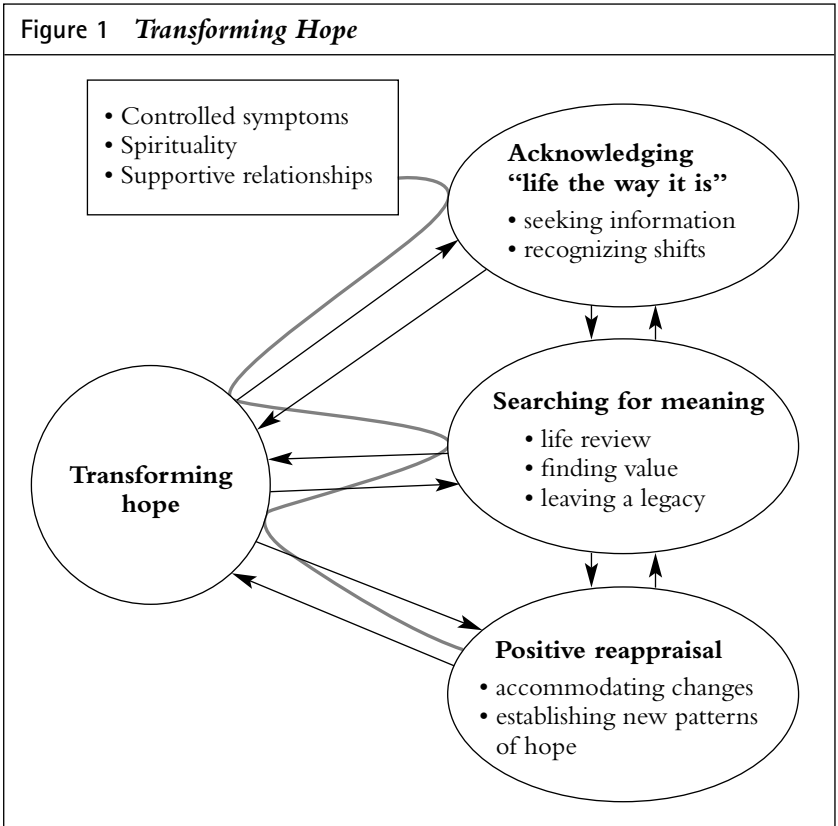
would not be present for the birth of a grandchild. One participant said: "I had things I wanted to do, things that we haven't done yet that I am not going to get around to doing… We had our retirement hopes…it changes, that's for sure." For other participants the process entailed their acknowledging that they had incurable cancer: "You have to accept the fact that you've got it…and if you don't accept that, you're suffering more the way you feel and your own feelings than you are with the disease that's killing you… [You have to] make up your mind that this is the way it is and this is life the way it is."

Searching for Meaning

Participants described searching for meaning as reflecting on and finding value in their lives: "I think you stop then and take a look at your-self…what you have accomplished. I think it all helps us in life, at least to keep hope." Finding meaning and value in their lives was also related to leaving a legacy, something of value. Participants described a legacy as

living on even when they were no longer alive: "It contributes to your hope to know that those will live on." This legacy was described as letters, gifts, contributions related to their careers, and, for some, their children and grandchildren. By finding meaning in their lives, the participants were able to view what was happening to them in a positive way.

Positive Reappraisal

By acknowledging their current situation and finding meaning and value in their lives, the participants were able to engage in positive reappraisal, and through reappraisal of their situation, expectations, and goals they were able to change their hope. Positive reappraisal was a process of accommodating life changes and establishing new patterns of hope. 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 and you just have to keep on going."

Discussion

The findings of this study are an emerging theory of hope within the context of the study participants. Glaser (1978, 1992) suggests that an emerging theory can contribute to the development of a formal grounded theory with broader scope and applicability. Elements of "transforming hope" may therefore contribute to the development of a hope theory for older palliative care patients.

The findings of this study are both similar to and different from those of other empirical work. The main concern of the participants, living with hope, was similar to that of the 11 palliative care patients in Benzein et al.'s (2001) study, who described "living in hope." In that study, the concept was described as reconciliation between life and death, whereby the participants were prepared for death in both practical and emotional ways. The dynamic nature of hope and the transformed focus of hope identified in the present study are also consistent with the findings of other studies (Benzein et al., 2001; Flemming, 1997; Hall, 1990; Herth, 1990). However, none of these studies addressed the transformative processes of hope.

Acknowledging "Life the Way It Is"

Acknowledging "life the way it is" was a process of transforming hope. Only one other study of hope reported palliative patients acknowledging or accepting their life situation. Benzein et al. (2001) describe acceptance as an aspect of reconciliation of life and death. However, they do not discuss how this acceptance influenced the hope of the participants.

Acknowledgement of "life the way it is" does not preclude the use of denial as a protective mechanism. Denial as a coping response may act as

a self-protection mechanism for palliative care patients, enabling them to defend themselves from threats and therefore enhancing their perception of control and self-efficacy (Russell, 1993). Hope is situational (Rustoen, Wiklund, Hanestad, & Moum, 1998), so denial could be used as a coping mechanism in one aspect of the participants' lives and acknowledging "life the way it is" in other aspects. The two concepts are not mutually exclusive.

The participants described hard facts as having helped them to acknowledge "life the way it is." It is possible that in this sense the participants were playing the role of a monitor who seeks information and wishes to have a larger part in decision-making. Miller's (1995) "blunters," in contrast, coped by not seeking information. Fallowfield, Jenkins, and Beveridge (2002), in a study with 1,046 palliative care patients, also identified the importance of health-care professionals' providing information; the majority of patients wished to receive as much data as possible, whether positive or negative. Benzein et al. (2001) found that lack of information contributed to uncertainty in palliative care patients. More research is needed to determine whether the method of information delivery has an influence on hope and how the concepts of monitors and blunters are related to the process of information delivery.

Searching for Meaning

The participants described searching for meaning as a sub-process of transforming hope, one aspect of which was life review. The concept of searching for meaning has been described in several hope studies with palliative patients (Benzein et al., 2001; Hall, 1990; Herth, 1990). An emergent theme in the Benzein et al. (2001) study was the patients' description of their lived experience of hope as the will to find meaning; for them, life review fostered reconciliation between life and death. Life review has also been found to be a mechanism for fostering hope among elderly residents of long-term-care facilities (Gaskins & Forte, 1995).

The participants also described the importance of leaving a legacy. Life review is focused on the individual, while leaving a legacy is focused on others. This finding is not reported in other studies of hope in palliative care patients. However, in a study of spirituality among palliative patients, the participants over 71 years of age said it was important to them to have accomplished something, whereas those under 71 did not (Thomas & Retsas, 1999). Therefore, leaving a legacy may be an aspect of searching for meaning that is specific to older palliative care patients. More research is needed to determine whether life review and leaving a legacy are linked to finding meaning and hope in other populations.

Positive Reappraisal

The participants' ability to interpret positively the changes in their lives was fostered by finding meaning in their lives. They described a process of reappraising their situation, expectations, and goals, the sub-processes of which were acknowledging "life the way it is" and finding meaning in life.

None of the published studies of hope among palliative patients describes the process of positive reappraisal. Benzein et al. (2001) describe envisioning a better future and Herth (1990) describes a positive outlook. However, these concepts are different from positive reappraisal, which is a cognitive change in perception of situation, expectations, and goals.

In a study with non-palliative, non-elderly breast cancer patients, Wonghongkul, Moore, Musil, Schneider, and Deimling (2000) found positive appraisal to be significantly associated with hope; with increased use of positive appraisal, hope increased. More research is needed to clarify the concept of positive reappraisal and its relationship to hope in palliative patients.

Transforming Hope

The participants in the present study described the sub-processes of transforming hope as interconnected. For example, without acknowledging their situation, they could not find meaning in their experience or use positive reappraisal of their experience in order to transform hope. All three of the sub-processes appeared to be important in transforming their hope. Transforming hope, as described by these participants, was more than the goal-setting and problem-solving that has been the focus of goal-setting theories of hope (Snyder, 2000; Stotland, 1969). Nekolaichuk and Bruera (1998) suggest that multidimensional models of hope reflect the palliative experience of hope more accurately than current theories of hope. The emerging theory of transforming hope discussed here is not only multidimensional but also adds conceptualization of hope as a transformative process with the three sub-processes. As well, the interrelationship of all the sub-processes and the concepts of symptom control, spirituality, and supportive relationships are not discussed in the palliative care literature.

Limitations

The study had several limitations related to the sample and methodology. The sample was 10 older palliative home-care patients living in rural Canada, so it is possible that category saturation as outlined by Glaser (2001) was not reached. The sample was relatively homogeneous. Palliative home-care patients in different geographic regions, of different ages and ethnicities, and with other religious or non-religious prefer-

ences, education levels, and incomes may describe their hope experience differently. As well, the participants had low symptom-intensity scores and high hope scores. The processes could differ for palliative patients with high symptom-intensity and/or low hope scores. Finally, given the increasing need to recognize the care requirements of patients with many end-stage illnesses, future research on hope should be conducted with individuals with diseases other than cancer.

Conclusion

It would be premature to generalize the findings of this study. However, the findings provide an empirical basis for informing our understanding of how palliative patients live with hope, and may serve as a basis from which to extend notions of hope captured in theories described in the literature. The sub-processes identified in the model provide a framework from which to conduct further research and to develop strategies for engendering hope in older palliative patients. The findings underscore the importance for nurses of symptom control and the fostering of spirituality and supportive relationships, as these measures are related to the process and sub-processes of hope. Nurses can also provide older palliative patients with information and can promote and facilitate life review, the leaving of legacies, and finding meaning in life. By actively engaging with older palliative care patients in these ways, nurses can foster hope that "enriches life and empowers individuals to live fully in greater aliveness, awareness and reason" (Fromm, 1968).

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2009 update: *Wendy Duggleby (PhD) and Karen Wright are Professors, College of Nursing, University of Saskatchewan. Dr. Duggleby leads the research program Living With Hope, comprising approximately 12 studies on hope.*