Meaningfulness in palliative home care: An interview study of dying cancer patients' next of kin

ANNA MILBERG, M.D. AND PETER STRANG, M.D., PH.D. 2

(RECEIVED March 1, 2003; ACCEPTED May 31, 2003)

ABSTRACT

Objective: An increasing number of patients are cared for at home and the presence of next of kin is often a prerequisite for successful home care. The aim of this study was to describe and interpret the construct of meaningfulness in next of kin of cancer patients who are in advanced palliative home care.

Methods: The perspective of Antonovsky's salutogenic framework of sense of coherence was applied in the analysis. Using a hermeneutic approach, 19 next of kin were interviewed (n = 30 interviews) during ongoing palliative home care.

Results: Elements that facilitated meaningfulness included comfort, retaining everyday life, action, commitment, and hope, which were of great importance for creating a perception of self-transcendence and that the best possible was done.

Significance of results: The findings are discussed in relation to the concepts of meaning-based coping, tragic optimism, and existentialism. Clinical implications are suggested.

KEYWORDS: Next of kin, Palliative home care, Coping, Sense of coherence, Meaningfulness

INTRODUCTION

Humans are meaning-seeking creatures (Frankl, 1946; Yalom, 1980). The desire to find meaning in our existence is a primary instinct and a basic motivation for human behavior (Breitbart, 2002). Meaning is also important to the individual's capacity to adjust and cope (Cassell, 1996; Davis et al., 1998), as expressed by Jung: "Meaning makes a great many things endurable—perhaps everything." (Yalom, 1980, p. 432) and by Nietzsche: "He who has a *why* to live can bear almost any 'how'" (Frankl, 1946, p. 10).

Corresponding author: Anna Milberg, Division of Geriatrics, Building 011, University Hospital, 581 85 Linköping, Sweden. E-mail: anna.milberg@lio.se

These ideas are highly applicable when a patient's condition deteriorates to a palliative stage, when death and dying cause crisis and distress not only in the patient, but also in the patient's next of kin (Sales et al., 1992; Kissane et al., 1994; Kristjanson & Ashcroft, 1994; Hodgson et al., 1997). The next of kin search for understanding and meaning, and ask—"Why has this happened to my beloved?" In addition, questions relating to the purpose of life are often raised: "What is the meaning of life?" (Doyle, 1992).

Church previously had a large influence on people's lives in Christian societies, and offered a framework for the search for meaning. However, the church's position has changed in secularized countries, and nowadays only 2.3% of the inhabitants in Sweden attend church regularly (Skog, 2001). This accelerating secularization contributes to the

¹Faculty of Health Sciences, Palliative Research Unit and Division of Geriatrics, Linköping University, Linköping, Sweden

²Karolinska Institutet and FoUU Stockholms sjukhem, Stockholm, Sweden

fact that each individual and family has to create their own meaning about life and death (Wikström, 1999), both in terms of sense making (i.e., meaning-as-comprehensibility) and benefit finding (i.e., meaning-as-significance; Davis et al., 2000).

In this sense, the meaning of life is not predetermined, neither for a group of people in a similar situation, nor for an individual over time. Instead, meaning can differ from person to person, from day to day and from hour to hour (Frankl, 1946, p. 113). Therefore, staff's ability to support next of kin in palliative care is dependent on knowledge of the specific meaning of each person's life at a given moment. However, a general knowledge of what meaning may consist of in this specific care context also seems important. For example, home as a place of care has special meaning for next of kin, positive as well as negative, during the care as well as during the bereavement (Milberg & Strang, 2000; Milberg, A., Strang, P., Carlsson, M., & Börjesson, S., submitted). In addition, family function and adequate support of the next of kin may be crucial for successful home care of dying patients and also as protection against subsequent postbereavement morbidity (Kissane et al., 1998; Cherny, 2000).

The concept of meaning has attracted different disciplines, for example, philosophers (Sartre, Nietzsche), psychiatrists (Frankl, 1946; Yalom, 1980; Kissane, 2000), psychologists (Folkman, 1997), medical sociologists (Antonovsky, 1987), chaplains (Speck, 1998), and palliative care physicians (Kearney) and nurses (Strang, 2002). This multiperspective interest mirrors the complexity of the concept and has resulted in illumination of diverse points. For example, the existentialist branch has concentrated on the individual's dealing with death, freedom, existential isolation, and meaninglessness (Yalom), whereas coping research has highlighted meaning-based coping, such as positive reappraisal, revised goals, spiritual beliefs, and positive events (Folkman, 1997). However, little research has so far been conducted concerning meaningfulness to next of kin during ongoing palliative home care (Davis et al., 1998), although it has been studied in related areas, for example, during bereavement (Yalom & Lieberman, 1991; Richards & Folkman, 1997; Richards et al., 1999) and group interventions for patients (Kissane et al., 1997; Breitbart, 2002). In addition, rarely have studies explored what specific positive aspects people seek (Park & Folkman, 1997).

Criticism has been raised due to lack of theoretical guidance in empirical research (Alderson, 1998; Davis et al., 1998; Folkman & Greer, 2000). Also, the importance of using accepted theories openly and logically has been stressed (Edman, 2000), and a theory that is grounded can be a platform in

the analysis to optimize the ability to reach new ground and deepen the understanding of a phenomenon in a more "mature" research area. Therefore, with focus on benefit finding (i.e., meaning-assignificance), Antonovsky's (1987) theory of sense of coherence (SOC) was chosen as a theoretical framework in this study.

SOC comprises three theoretical concepts: (1) comprehensibility—a perception that the challenge is understood, (2) manageability—a perception that the resources to cope are available, and (3) meaningfulness—a wish and motivation to cope (Antonovsky, 1996). SOC was developed as a salutogenic orientation that considers health-disease as a continuum, with focus on general resistance resources, as opposed to a pathogenic orientation viewing health-disease as a dichotomy with focus on risk factors and treatment of illness.

When initiating the present study, the primary intention was to study all three aspects of SOC. However, the concepts of comprehensibility and manageability and the process involved in the next of kin's dealing with all three aspects of SOC appeared to be very extensive, and hence will be presented separately. Therefore, in this article, the focus is on the construct of meaningfulness.

The aim of this report is to describe and interpret the construct of meaningfulness of cancer patients' next of kin in advanced palliative home care from the perspective of Antonovsky's salutogenic framework of sense of coherence.

MATERIAL AND METHODS

Setting

The study was performed in a Swedish advanced palliative hospital-based home care (HBHC) setting. The multiprofessional teams included doctors, nurses, auxiliary staff, occupational therapists, physiotherapists, and social workers. Doctors, nurses, and auxiliary staff were available around the clock within half an hour when needed. Further, a back-up ward was available to each of the teams (Beck-Friis & Strang, 1993; Rosenquist et al., 1999).

Subjects

Nineteen adult Swedish-speaking next of kin of cancer patients in three HBHC teams in the county of Östergötland were included. The next of kin were chosen according to maximum variation sampling technique (Crabtree & Miller, 1992, pp. 38), using background variables to get as broad a range of the

phenomenon as theoretically possible. Characteristics of the informants are presented in Table 1.

Data Collection

Cancer patients' next of kin were asked by HBHC staff whether they were interested in participating in the study; this was followed by a covering letter. The study was approved by the local research ethics committee.

Those who consented were then phoned by the interviewer (the first author). Tape-recorded interviews (about 30–60 min; in 1998–2001) were performed one to three times during the actual HBHC care and transcribed verbatim. The initial interview focused on the informant's experience being the next of kin of a patient referred to the HBHC program. Open-ended questions were addressed, such as "How is it to be a next of kin to a patient that is referred to HBHC?" "Have you experienced a situation that has been difficult (or positive) in some way during the care? Would you like to tell me about that?" "How did you manage?" "Could the health care staff have facilitated for you?" "If so, in

Table 1. Characteristics of the 19 next of kin (i.e., the informants) and 19 patients, gathered in 30 interviews

Gender (women/men) (n) Age in years (median (range))	10/9 67 (45–78)
Education Elementary (n) High school (n) University (n)	13 3 3
Employed (n)	7
Relationship to patient Married or cohabiting (n) Child (n)	15 4
Shared accommodation with patient (n)	16
Patients' age in years (median (range)) Patients' gender (no. of women)	72 (57–86) 11
Origin of patient's malignancy (n) Breast Prostate Bowel Lung/thymus/mesothelial tissue Ovary/pancreas/urinary bladder/ lymphatic tissue Uncertain	4 4 2 4 1
Interviews Duration of patient in HBHC 1-3 months (n) >3 months (n)	18 12

what way?" "What has this situation meant to you afterwards?" Subsequent interviews explored issues/situations raised previously by the informants, while also allowing other issues to emerge as the health of the patient deteriorated.

Theoretical Framework and Analysis

Hermeneutics has historically dealt with the interpretation of texts of the humanities, especially biblical texts, but has lately been extended to the interpretation of the object of the social sciences meaningful action—and referred to as existential hermeneutics (Kvale, 1996). Seven canons of a hermeneutic meaning interpretation (adapted and extended by Kvale, 1996, pp. 46–50; Radnitzky, 1970) guided the analysis in the present study: (1) continuous back and forth process between the parts and the whole (hermeneutic circle [or spiral]); (2) interpretation of meaning ends when one has reached a "good Gestalt," an inner unity of the text free of logical contradictions; (3) testing of part interpretations against the global meaning of the text; (4) autonomy of the text, that is, the text should also be understood on the basis of its own frame of reference; (5) hermeneutical explication of a text concerns knowledge about the theme of the text; (6) an interpretation of a text is not without presuppositions; and (7) every interpretation involves innovation and creativity.

The analysis was performed through naive reading, decontextualization, and recontextualization. The predefined component (meaningfulness) was applied to the text while coding, as a preconceived aspect to be studied. This means that the categories for classifying the text emerged from the analysis and were not preconceived, although the theoretical concept to be illuminated by the developing categories were predetermined.

Trustworthiness

The interviews were conducted at a place according to the next of kin's wishes (at home in a room separate from the patient, at the geriatric outpatient clinic, or, in one case, at the next of kin's office), to ensure a milieu as confidence-inspiring as possible for the informants (corresponding to credibility/"internal validity"; Guba, 1981). Initially, five interviews were coded separately by each author and there was good agreement concerning the concepts' (i.e., meaningfulness in this article) application to the text (corresponding to dependability/"reliability"; Guba, 1981). The coding and development of categories were done mainly by the first author. Themes and patterns that were salient

in the interviews were isolated by the first author and then validated by the second author as to their relevance and applicability in the material (corresponding to confirmability/"objectivity"; Guba, 1981). Involving several researchers (in this study two) may strengthen the research design, not through achievement of consensus or identical statements, but by supplementing and contesting each others' readings, as part of reflexivity (Malterud, 2001) and broadened pre-understanding.

RESULTS

The results are presented in sections entitled "parts" and "as a whole." "Parts" of meaningfulness concern different dimensions important to next of kin. "As a whole" regards meaningfulness to the next of kin at a higher abstraction level. Five categories concerning parts of meaningfulness (comfort, retaining everyday life, action, commitment, and hope) and two that concerned meaningfulness as a whole (self-transcendence and doing the best possible) were identified. The categories are described below, and an overview of the constructs of meaningfulness is shown in Figure 1. The interview focus was on meaningfulness, but meaninglessness was also illuminated. Although the results are presented, for pedagogical reasons, in a dichotomous way, for example, hope versus hopelessness, they should be understood as more complex and continuous aspects of the next of kin's experience, fluctuating with time and context.

Parts

Comfort

It was positive to next of kin to perceive that the patient experienced comfort, but comfort of other family member was also important. Comfort contained several positive and negative aspects of wellbeing, such as physical, psychological, existential, and social. Both explicit verbal and implicit nonverbal feedback from the patient was important in the next of kin's assessment of the patient's comfort.

Care at home facilitated the next of kin's assessment of the patient's comfort. Much time was spent together and thereby next of kin could follow the situation, as opposed to having to adapt to the conditions at the hospital, for example, limited visiting hours and roommates' need for privacy at the hospital.

Yes, that is, of course, pleasant, as I see all day long how he is. Should he be in hospital, I would perhaps go there once a day; that'd be just for a while. . . . As it is now the nights can sometimes be tiresome. When he wakes up I wake up and then it takes a good while before I can fall asleep again. But in any case, I take part, I see, of course, all changes there are and how he feels. . . . You hear from his voice how he feels too. You hear from his breathing, which one wouldn't do if he were in hospital. To know if it sounds good or if, today it's not so well. You know exactly. (70-year-old wife)

Retaining Everyday Life

It was encouraging to next of kin when the every-day life of the patient and the family could be retained as much as possible. Habits, hobbies, celebrations of festivities despite illness, spending of weekends and holidays, and the company of friends all were significant and appreciated attributes. The specific make-up of such everyday life aspects reflected the unique way the patient as well as the family had chosen to live. When previous habits could not be continued as they used to and there was no normalcy, everyday life was threatened and created suffering.

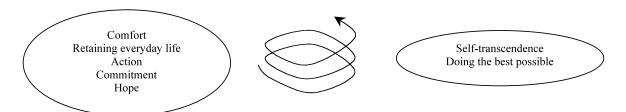


Fig. 1. Overview of next of kin's dealing with the concepts of meaningfulness. The left circle contains dimensions of meaningfulness important to next of kin. The right circle shows next of kin's relation to the dimensions of meaningfulness in his/her present situation at a more abstract level. The content of the circles refers to both present and nonpresent aspects, e.g., "comfort" means both comfort and deficiency of comfort, i.e., discomfort. The spirals symbolize the back and forth movement between aspects of parts (left circles) and whole (right circles) in the human understanding process according to a hermeneutic perspective.

But it is really quite a big difference how we live. In reality, we don't do much now, you know. Everything changes . . . eating habits are totally different, you see. Well, we used to eat good food and we have spent a good deal on food and today I don't think either of us is particularly fond of food. Weekends are difficult. I don't know what to think of and so on. Since she doesn't have very much appetite, then I don't have either. (57-year-old husband)

Retaining everyday life was often dependent on abilities such as eating, visiting the toilet, and having enough strength to join the family dinner table, whereas loss of physical, psychological, or social abilities was highly negative. Care at home had contributed to a large amount of time spent together. Although the situation was changed due to the palliative stage of illness, there were still important aspects remaining.

I notice that he has become much more tired than he was before. He has, you see, so many cats that he feeds. Earlier they were up there at the cowshed there, but now he feeds them on the doorstep down here. He won't go over there. So it has become a bit worse then, you know. Some weeks ago, then he could go out and walk up to the cowshed up there, you know. (76-year-old wife)

Action

Action comprised serving, protecting and also a means of distraction, mostly as regards the patient, but sometimes also regarding the family. Serving involved both activities the patient would normally have done by her/himself if she/he had not been ill, and more altruistic-oriented ones, for example cooking the patient's favorite dishes.

[Fifty-three-year old daughter had helped her mother to perm her hair] Mother seemed very much happier and she was really very positive. That you take in. It is fun such moments. For her it's important, super important. Because you know when they shower and your hair is hanging about. She has such thin hair, and then it hangs straggling and she doesn't want to look like that, instead she wants to keep herself in order. So then she was tremendously pleased.

Protecting the patient from negative feelings was done by being "strong" and not showing signs of stress, and by hiding feelings. Other times, action was mainly done for the purpose of distraction or to counteract a sense of helplessness. Home as the place of care was perceived to facilitate the opportunities for acting.

Yes, it's of course that she has been let home. She is back home in her flat again. There is something for me to do. I can go and buy a litre of milk, I can go up and see her when it's needed, I can take her out for a walk or so. At least I keep myself busy and that is important for me. We feel it's mentally better when she is at home. Even though she is as ill as she was some weeks ago and then was at the hospital, I still feel it's better to have her at home. (45-year-old son)

Commitment

A majority described a strong commitment emanating from two main sources: responsibility and love. The involvement in the care of the patient was for some a responsibility, something you had to do that was not to be questioned, whereas others emphasised love, for instance, a wish to repay the previous positive things the patient had contributed to the next of kin. Several next of kin had made explicit promises to the patients about not caring for them out of home in case of severe illness. The promises had been made long ago or at the time of the diagnosis.

None of the informants expressed feelings of total lack of commitment. However, some next of kin described a lack of motivation originating in discomfort, loss of everyday life, and lack of options for action.

Hope

Hope concerned the same content as expressed by meaningfulness, that is, different aspects of comfort and retaining everyday life, but in addition a temporal aspect of possible experience of future meaningfulness was included. Through hope, next of kin projected meaningfulness into the future, and then there was something potentially meaningful to look forward to, for example, patient's comfort. In contrast, when filled with hopelessness there was no hope of future meaningfulness.

As a Whole

Self-Transcendence

The next of kin transcended her/his self-interest and strove towards something outside or "above" her-/himself. This self-transcendence was the basis for commitment, action, comfort, and retaining every-day life, that is, the next of kin had a commitment to act with the aim of best comfort and closeness to

everyday life for the patient. The perception that the patient was feeling well also had a positive influence on the next of kin's mood.

Interviewer: "Do you find your situation meaningful?"

Next of kin: "Yes, it is, greatly."

Interviewer: "What is it that makes it meaningful?"

Next of kin: "Well, that is to say, I am, of course, I am at hand and can help out, you see. It would be a disaster if I were not as well as I am. There would be great difficulties then. . . . You do it out of love for the one you nurse . . . you do what you can so that the one who is ill will be comfortable." (75-year-old husband)

Doing the Best Possible

To feel that the best possible had been done for the patient was central to next of kin. This experience related to self-transcendence, but also included another aspect. It was not only that something meaningful had been done for the patient. In addition, it concerned the next of kin's awareness and acceptance of some negative, meaningless unchangeable aspects in the patient's situation. Despite those aspects, next of kin perceived that something meaningful had been done, that is, the best possible meaning-contributing aspects under meaningless circumstances.

Promoting survival was important, but when next of kin had realized that this was impossible to influence and accepted that nothing could change this, then focus of meaning was directed to other aspects of action to increase well-being.

We have tried in so many different ways to stop this cancer tumour, which is spreading. And it seems to be nearly hopeless, you know! And therefore I also wish to do the best possible for my husband, you know, so that he will not [suffocate]. (61-year-old wife)

In contrast, next of kin felt powerlessness and helplessness when there was nothing concrete he/she could do or contribute with as regards symptoms and comfort.

Next of kin: "Oh yes, yes it was for 4–5 days you know, that he did not eat anything. There was NOTHING that he could eat and I asked if he wanted something special, but he did not want

anything I suggested. 'No I cannot' he said. And when he ate he threw it up. He threw up all of it. . . . Yes it was of course terribly tough. Well, it was terribly tough. . . ."

Interviewer: "... And what did you do to handle this situation?"

Next of kin: "Yes, what did I do (whispering) there wasn't much to do actually." (62-year-old wife)

DISCUSSION

As the discipline of palliative medicine matures, it is becoming more apparent that concepts of adequate palliative care must be expanded in their focus beyond pain and physical symptom control to include existential and spiritual issues such as meaning (Kissane, 2000; Breitbart, 2002). In this study the construct of meaningfulness was investigated from a salutogenic perspective concerning the next of kin of dying cancer patients who had been referred to advanced palliative home care. The main picture that emerged from the analyses concerned comfort, retaining everyday life, action, commitment, hope, self-transcendence, and doing the best possible. The significance of these aspects is supported by other studies of next of kin of palliative patients during ongoing care (Brown et al., 1990; Hull, 1990; Steele & Fitch, 1996; Andershed & Ternestedt, 2001; Grbich et al., 2001; Strang & Strang, 2001), of palliative patients (Cameron & Parkes, 1983; Salander et al., 1996; Hodgson et al., 1997; Breitbart, 2002), in the general palliative or coping literature (Lazarus & Folkman, 1984; Doyle & Jeffrey, 2000; Kinsella et al., 2000). However, few previous studies have focused specifically on meaningfulness for next of kin of patients in palliative home care, and the present study revealed aspects that have not been much illuminated in earlier literature and that seem important for the clinical situation. The findings relate to the concepts of meaning-based coping (Folkman, 1997), tragic optimism (Frankl, 1946), and existentialism as expressed by Yalom (1980).

Methodological Considerations

Neither the informants nor the patients were younger than 45 years. In addition, none of the informants expressed feelings of total lack of commitment. This has consequences for the transferability of the results to other ages and other degrees of commitment. The informants did not make a clear separation in the narratives between their experiences before the referral and during advanced palliative home care, although they were asked about their

experience during the latter. This could lead to questions of data contamination. However, it turned out that earlier experiences of health care were important pieces of information, because the informants often contrasted their experience in palliative home care with that before the referral, and a separation would have been artificial.

Meaningfulness—Possible Also during Ongoing Palliative Home Care

Although the cooccurrence of positive and negative aspects throughout caregiving initially seems paradoxical, this study showed that the ability to achieve positive states of mind was not totally compromised by the stress and burden of caregiving, and this is also supported by other studies (Folkman, 1997; Grbich et al., 2001). In fact, meaningfulness has proved to be both important and frequent in relation to coping and in the context of severe illness. In a study of spouses or partners of men dying from AIDS, positive meaningful events were reported in 99.5% of the 1,794 interviews that asked about them (Folkman, 1997). These findings have led to a revision of the previously dominant stress-appraisalcoping theory by Lazarus and Folkman, and the revised theory also takes positive psychological states and meaning-based coping into account (Lazarus & Folkman, 1984; Folkman, 1997). By including meaningful aspects in coping theory, the focus has changed from distress such as psychiatric symptoms to the possibility and significance of psychological well-being and meaningfulness, as well. This theoretical shift seems important to goal setting in palliative care.

Meaningfulness—Indeed a Concept for the Practitioner to Consider during Contact with the Family

In the present study, next of kin also expressed, in addition to meaningfulness, sources of meaninglessness in their narratives. However, the general ability on the part of the staff to formulate and execute a clinical response to the problem of meaninglessness seems to be limited, as indicated by a significant difference between a positive staff attitude concerning spiritual care and limited real occurrence of spiritual care at the staff's own units (Strang et al., 2002). Why is this so? Meaninglessness requires an increased understanding, and failure to appreciate or to effectively address the full diversity of contributing factors may confound effective therapeutic strategies. This has been pointed out by Cherny (2000) concerning dignity, and seems also relevant in the context of meaningfulness. To respond to meaninglessness, the sources of meaningfulness as well as meaning of meaningfulness to next of kin in palliative home care have to be known and therapeutic strategies developed. Such strategies including meaning aspects, have also been proposed by several authors in the context of palliative care (Folkman & Greer, 2000; Kissane, 2000; Rousseau, 2000; Lo et al., 2002; Strang, 2002).

But why should staff care about meaningfulness at all? From a philosophical existentialistic perspective it is the individual's own responsibility and freedom to create meaning, and life is meaningless until the individual fills it with meaning (Frankl, 1946, p. 114; Yalom, 1980, p. 431). It has also been stressed that meaning cannot be imposed or given by someone else (Kearney, 2000). However, obviously the palliative care team can facilitate, but not impose, meaning as concluded in the current data. This study stressed the interactional dimension of meaningfulness, for example, next of kin's involvement in activities in a context where the palliative home care staff was interacting as well. Perception of meaninglessness such as loss of everyday life, hopelessness, and limited possibilities for action seem to constitute possible starting points for formulations of therapeutic responses to meaninglessness in next of kin (Table 2), which is supported in the context of dying patients although not previously specifically studied in the context of next of kin (Folkman & Greer, 2000; Kearney, 2000; Kissane, 2000).

Significance of Retaining Everyday Life, Action, and Doing the Best Possible

The impact of retaining everyday life or normalcy has also been pointed out by others (Brown et al., 1990; Folkman, 1997). It includes facets of preserved identity and uniqueness, which relates to what Yalom (1980, p. 464) has concluded concerning how one creates oneself by a series of ongoing decisions. Retaining normalcy also relates to Cassell's (1996, pp. 73–74) definition of suffering, that is, suffering is closely associated to any event that threatens a person in a wide sense: physically, emotionally, existentially, or socially.

Although changes in everyday life due to severe illness of a family member or close friend cannot be totally prevented, the study results emphasize the importance of limiting the intrusion into this unique construction as much as possible. Aspects important in such discussions could be, for example, visits correlated to the family's schedule, helpful aids to maintaining certain patient's activities, and when possible avoiding negative changes in home envi-

Table 2. Possible therapeutic response to the identified hindrances of meaningfulness

Hindrances to meaningfulness		
Discomfort	Effective symptom control	
Loss of everyday life	Limitation of intrusion into the family's everyday life, e.g., staff visits, changed home environment	
	Preserving patient's functional ability via aids	
Lack of activity	Facilitation of next of kin's participation in caring activities of the patient	
	Facilitation of distracting activity for next of kin	
Hopelessness	Assistance in redefining hope, e.g., via realistic goal setting	
Lack of self-transcendence	Reassurance that next-of-kin contributes to something "above" her-/himself	
Powerlessness-helplessness	Reassurance that best possible is done	

ronment such as bulky aids. However, only the family can define the aspects that are of greatest importance for them to preserve.

The finding of self-transcendence has been discussed earlier by others (Frankl, 1946, p. 147; Yalom, 1980, p. 439). However, "doing the best possible" has been less investigated, although acknowledged from a clinical view (Doyle & Jeffrey, 2000, p. 76). Our findings of the significance of doing the best possible seem closely related to the concept of tragic optimism (Frankl, 1946, p. 2). Tragic optimism is described as optimism in the face of tragedy. The concept of doing the best possible stresses the fact that the coping process does not have to cease despite events with unsatisfactory outcomes. Instead, continuation is possible and this has also been included in Folkman's revised theoretical model (Folkman, 1997). Therefore, it seems important in palliative care to strengthen the next of kin's perception that the best possible is being done and that the next of kin contributes to significant things "above" her-/himself. One way for the practitioners to do this seems to involve active reassurance of next of kin (when appropriate) that such is actually being done, both concerning the next of kin's and the health care staff's participation.

Although relief of symptoms such as pain is indeed desirable also from the perspective of next of kin (Cherny, 2000, p. 376) this study showed that symptom control is only one of several factors contributing to next of kin's perception of meaningfulness. Therefore, if research findings should guide clinical practice (Folkman & Greer, 2000), goal setting in palliative care should not only include symptom control, but also other factors, such as retaining everyday life, action, commitment, and hope. In addition, goal setting at a higher abstraction level should be considered, goals such as self-transcendence and doing the best possible. For-

mulation of therapeutic responses to meaninglessness seem possible, and suggestions are summarized in Table 2.

ACKNOWLEDGMENTS

We thank Eva-Carin Olsson and other staff members of the three HBHC teams involved in Östergötland for various kinds of help, and Monica Ulriksson for typing the interviews. Financial support was given by Cancerfonden, the County Council of Östergötland (Kommittén för medicinsk forskning och utveckling; ALF) and the Thureus Fund.

REFERENCES

Alderson, P. (1998). The importance of theories in health care. *British Medical Journal*, 317, 1007–1010.

Andershed, B. & Ternestedt, B.M. (2001). Development of a theoretical framework describing relatives' involvement in palliative care. *Journal of Advanced Nursing*, 34, 554–562.

Antonovsky, A. (1987). *Unravelling the Mystery of Health: How People Manage Stress and Stay Well.* San Francisco: Jossey-Bass Publishers.

Antonovsky, A. (1996). The salutogenetic model as a theory to guide health promotion. *Health Promotion International*, 11, 11–18.

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.

Breitbart, W. (2002). Spirituality and meaning in supportive care: Spirituality- and meaning-centered group psychotherapy interventions in advanced cancer. Supportive Care in Cancer, 10, 272–280.

Brown, P., Davies, B., & Martens, N. (1990). Families in supportive care–Part II: Palliative care at home: A viable care setting. *Journal of Palliative Care*, 6, 21–27.

Cameron, J. & Parkes, C.M. (1983). Terminal care: Evaluation of effects on surviving family of care before and after bereavement. *Postgraduate Medical Journal*, 59, 73–78.

- Cassell, E.J. (1996). Lidandets natur och medicinens mål [The nature of suffering and the goals of medicine]. Lund: Studentlitteratur.
- Cherny, N.I. (2000). The treatment of suffering in patients with advanced cancer. In *Handbook of Psychiatry in Palliative Medicine*, Chochinov, H.M. & Breitbart, W. (eds.), pp. 375–396. Oxford: Oxford University Press.
- Crabtree, B.F. & Miller, W.L. (1992). Doing Qualitative Research. Newbury Park, CA: Sage.
- Davis, C.G., Nolen-Hoeksema, S., & Larson, J. (1998). Making sense of loss and benefiting from the experience: Two construals of meaning. *Journal of Personality and Social Psychology*, 75, 561–574.
- Davis, C.G., Wortman, C.B., Lehman, D.R., & Silver, R.C. (2000). Searching for meaning in loss: Are clinical assumptions correct. *Death Studies*, 24, 497–540.
- Doyle, D. (1992). Have we looked beyond the physical and psychosocial? *Journal of Pain and Symptom Management*, 7, 302–311.
- Doyle, D. & Jeffrey, D. (2000). Palliative Care in the Home. Oxford: Oxford University Press.
- Edman, M. (2000). Skeptikern och verkligheten. Kontinuerliga samband mellan goda och dåliga teorier [The skeptic and reality. Continuous connection between good and bad theories]. *Läkartidningen*, 97, 593–597.
- Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science & Medicine*, 45, 1207–1221.
- Folkman, S. & Greer, S. (2000). Promoting psychological well-being in the face of serious illness: When theory, research and practice inform each other. *Psycho-Oncology*, 9, 11–19.
- Frankl, V.E. (1946). Man's Search for Meaning. Boston: Beacon Press, 1992 edition.
- Grbich, C., Parker, D., & Maddocks, I. (2001). The emotions and coping strategies of caregivers of family members with a terminal cancer. *Journal of Palliative Care*, 17, 30–36.
- Guba, E.G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Education Communication and Technology*, 29, 75–91.
- Hodgson, C., Higginson, I., McDonnell, M., & Butters, E. (1997). Family anxiety in advanced cancer: A multicentre prospective study in Ireland. *British Journal of Cancer*, 76, 1211–1214.
- Hull, M. (1990). Sources of stress for hospice caregiving families. *Hospice Journal*, 6, 29–54.
- Kearney, M. (2000). Spiritual care of the dying patient. In *Handbook of Psychiatry in Palliative Medicine*, Chochinov, H.M. & Breitbart, W. (eds.), pp. 357–373. Oxford: Oxford University Press.
- Kinsella, G., Cooper, B., Picton, C., & Murtagh, D. (2000). Factors influencing outcomes for family caregivers of persons receiving palliative care: Toward an integrated model. *Journal of Palliative Care*, 16, 46–54.
- Kissane, D.W. (2000). Psychospiritual and existential distress. The challenge for palliative care. *Australian Family Physician*, 29, 1022–1025.
- Kissane, D., Bloch, S., Burns, W., McKenzie, D., & Posterino, M. (1994). Psychological morbidity in the families of patients with cancer. *Psycho-Oncology*, 3, 47–56.
- Kissane, D., Bloch, S., McKenzie, M., McDowell, A., & Nitzan, R. (1998). Family grief therapy: A preliminary account of a new model to promote healthy family functioning during palliative care and bereavement. *Psycho-Oncology*, 7, 14–25.

- Kissane, D.W., Bloch, S., Miach, P., Smith, G.C., Seddon, A., & Keks, N. (1997). Cognitive-existential group therapy for patients with primary breast cancer—techniques and themes. *Psycho-Oncology*, 6, 25–33.
- Kristjanson, L.J. & Ashcroft, T. (1994). The family's cancer journey: A literature review. *Cancer Nursing*, 17, 1–17.
- Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage.
- Lazarus, R.S. & Folkman, S. (1984). Stress, Appraisal and Coping. New York: Springer Publishing Company, Inc.
- Lo, B., Ruston, D., Kates, L.W., Arnold, R.M., Cohen, C.B., Faber-Langendoen, K., Pantilat, S.Z., Puchalski, C.M., Quill, T.R., Rabow, M.W., Schreiber, S., Sulmasy, D.P., & Tulsky, J.A. (2002). Discussing religious and spiritual issues at the end of life: A practical guide for physicians. Journal of the American Medical Association, 287, 749–754.
- Malterud, K. (2001). Qualitative research: Standards, challenges, and guidelines. *Lancet*, 358, 483–488.
- Milberg, A. & Strang, P. (2000). Met and unmet needs in hospital-based home care: Qualitative evaluation through open-ended questions. *Palliative Medicine*, 14, 533–534.
- Park, C. & Folkman, S. (1997). Meaning in the context of stress and coping. *Review of General Psychology*, 1, 115–144.
- Radnitzky, G. (1970). Contemporary Schools of Metascience. Gothenburg, Sweden: Akademiförlaget.
- Richards, T.A., Agree, M., & Folkman, S. (1999). Spiritual aspects of loss among partners of men with aids, postbereavement follow-up. *Death Studies*, 23, 105–127.
- Richards, T.A. & Folkman, S. (1997). Spiritual aspects of loss at the time of a partner's death from AIDS. *Death Studies*, 21, 527–547.
- Rosenquist, A., Bergman, K., & Strang, P. (1999). Optimizing hospital-based home care for dying cancer patients: A population-based study. *Palliative Medicine*, 13, 393–397.
- Rousseau, P. (2000). Spirituality and the dying patient. Journal of Clinical Oncology, 18, 2000–2002.
- Salander, P., Bergenheim, T., & Henriksson, R. (1996). The creation of protection and hope in patients with malignant brain tumours. Social Science and Medicine, 42, 985–996.
- Sales, E., Schulz, R., & Biegel, D. (1992). Predictors of strain in families of cancer patients: A review of the literature. *Journal of Psychosocial Oncology*, 10, 1–26
- Skog, M. (2001). Det religiösa Sverige: gudstjänst-och andaktsliv under ett veckoslut kring milliennieskiftet. Örebro, Sweden: Libris.
- Speck, P. (1998). Spiritual issues in palliative care. In Oxford Textbook of Palliative Medicine, Doyle, D., Hanks, G.W.C., & MacDonald, N. (eds.), pp. 805–814. Oxford: Oxford University Press.
- Steele, R.G. & Fitch, M.I. (1996). Coping strategies of family caregivers of home hospice patients with cancer. *Oncology Nursing Forum*, 23, 955–960.
- Strang, S. (2002). Spiritual/Existential Issues in Palliative Care with Special Reference to Patients with Brain Tumours and Their Spouses. Ph.D. thesis. Institute of Selected Clinical Sciences, Department of Oncology, Göteborg University, Göteborg, Sweden.
- Strang, S. & Strang, P. (2001). Spiritual thoughts, coping

and 'sense of coherence' in brain tumour patients and their spouses. $Palliative\ Medicine,\ 15,\ 127-134.$

- Strang, S., Strang, P., & Ternestedt, B.M. (2002). Spiritual needs as defined by Swedish nursing staff. *Journal of Clinical Nursing*, 11, 48–57.
- Wikström, O., 1999. I livets slutskede: Dödsångest [In the End of Life: Death Anxiety], Stockholm: Socialstyrelsen.
- Yalom, I.D. (1980). Existential Psychotherapy. New York: Basic Books, Inc.
- Yalom, I. & Lieberman, M. (1991). Bereavement and heightened existential awareness. *Psychiatry*, 54, 334–345.