EXPANDING COMPREHENSIBILITY AND MANAGEABILITY IN PALLIATIVE HOME CARE: AN INTERVIEW STUDY OF DYING CANCER PATIENTS’ INFORMAL CARERS

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SUMMARY
The presence of an informal carer is often a prerequisite for successful palliative home care, and the staff’s ability to support informal carers’ coping in such situations is important. Recent research has revealed that it is possible to achieve positive psychological states in palliative care despite the burdening situation. As there is a lack of theory-based coping studies, the aim of this study was to describe, within the context of palliative home care, two concepts in Antonovsky’s theory of Sense of Coherence: comprehensibility (a perception that the challenge is understood) and manageability (a perception that the resources to cope are available). Tape-recorded semi-structured interviews with 19 informal carers during ongoing palliative home care were transcribed and analysed with a qualitative hermeneutic approach. Elements that facilitated comprehensibility included open information, symbolic information, basic life assumptions and previous knowledge. These were important for creating a congruent inner reality (as opposed to chaos). Resources contributing to manageability dealt with power, support, competence and accessibility, which on a more abstract level resulted in a feeling of togetherness (as opposed to isolation). The findings are discussed in relation to the complexity of communication between staff and carers within palliative care. Copyright © 2003 John Wiley & Sons, Ltd.

INTRODUCTION
Death and dying cause crisis not only in the patient, but also in the patient’s informal carers (Kristjanson and Ashcroft, 1994; Sales et al., 1992). Knowledge about their situation in palliative home care is important because: (i) an increasing number of patients is cared for at home (Higginson et al., 1990), (ii) the presence of informal carers is often a prerequisite for successful home care (Hinton, 1994), and (iii) home as a place of care seems to have special aspects—mainly positive but also negative, during the care as well as after the death of the ill family member (Milberg and Strang, 2000; Milberg et al., 2003).

The staff’s ability to support in such situations is dependent on their understanding of the individual, and an important way is by using the concept of coping (Grbich et al., 2001; Harding and Higginson, 2001; Hull, 1992). As Folkman has pointed out: ‘Coping may have a relatively small influence on adjustment and recovery compared to factors such as the timing and nature of the death, history and personality. Nonetheless, as the extensive popular and clinical literatures indicate, coping is important because it is one of the few factors influencing bereavement outcomes amenable to brief interventions’ (Folkman, 2002, p. 564).

Coping theory has traditionally focused on stress (Folkman, 1997). However, there is growing evidence of the possibility of achieving positive psychological states despite a stressful situation (Folkman, 1997), such as being an informal carer to a dying family member or friend (Grbich et al., 2001; Park and Folkman, 1997). For example, in a study of spouses or partners of men dying from...
AIDS, positive meaningful events were reported in 99.5% of the 1794 interviews that asked about them (Folkman, 1997), and these events were significant experiences according to the participants. Such findings have challenged the previously dominating stress-appraisal-coping model by Lazarus and Folkman (1984), and new or revised coping models have been developed of how humans deal with burdening situations, such as death, dying and bereavement. Two models of influence that have changed from an initial cognitive focus to a more meaning-based approach are Folkman’s revised model (Folkman, 1997) and Antonovsky’s theory of Sense of coherence (SOC) (Antonovsky, 1987). Other important contributors within this research area are e.g. Kobasa’s theory of hardiness (Kobasa, 1979), Rotter’s Locus of control (Rotter, 1966), Moss’ Context and coping (Moos, 1984), Boyce’s concepts of Sense of permanence (Boyce et al., 1983; Jensen et al., 1983), and Seligman’s theory of Learned optimism (Seligman, 1991).

A totally inductive analysis is usually perceived as the ideal approach and aim in a qualitative study. However, in a more ‘mature’ research area when there are accepted well-founded theories, these may in fact be important to use openly, and consequently as a platform in further analysis and conceptualisation to optimise the ability to reach new ground and deepen the understanding of a phenomenon (Edman, 2000). Moreover, criticism has been raised due to the lack of such theoretical guidance in empirical coping and palliative research (Alderson, 1998; Davis et al., 1998; Folkman and Greer, 2000; Kinsella et al., 1998), both concerning explorative designs and in instrument development, such as measurement of family and caregiver burden of palliative care. If we accept salutogenic, meaning-based coping theories also in the palliative context, this should have consequences for how research is designed, instrument constructed and for clinical practice. Therefore, this study was designed with a clear theoretical framework, namely Antonovsky’s theory of salutogenesis (Antonovsky, 1987).

Aaron Antonovsky was a medical sociologist who developed the theory of Sense of coherence (SOC) when he was working with female survivors of the Second World War. Despite such stressful experiences, some of the women stated that they had a rather good physical as well as mental health. How could that be understood? In his analysis he found that this had to do with an inner overarching Sense of coherence, that is ‘a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one’s internal and external environments in the course of living are structured, predictable, and explicable [i.e. comprehensibility]; (2) the resources are available to one to meet the demands posed by these stimuli [i.e. manageability]; and (3) these demands are challenges, worthy of investment and engagement [i.e. meaningfulness]’ (Antonovsky, 1987, p. 19).

SOC has an underlying assumption about health and illness that contrasts with that of the traditional biomedical model, that is the dominating paradigm within Western health care. Antonovsky described this as a salutogenic orientation as opposed to the biomedical model’s pathogenic one. The salutogenic orientation views health and disease as a continuum, as opposed to the pathogenic one, which considers it as a dichotomy. This difference has consequences for the goals of medicine and health care. A salutogenically based health care service focuses on ‘how can we understand and facilitate movement of people in the direction of the health end of the continuum?’. As opposed to the pathogenically based service, which concentrates on ‘what are the risk factors?’ and ‘how can we cure or prevent disease?’?

Antonovsky also developed an instrument, which was based on his theory and the three aspects of SOC. The instrument has been criticised, because it has shortcomings and does not reflect the underlying concept well enough (Tishelman et al., 1991). However, this instrument is only one way of assessing SOC, and in his book Antonovsky stressed the value of using different methods when exploring the concept, including qualitative approaches (Antonovsky, 1987, pp. 90–91). Therefore, when initiating the present study the theoretical perspective of SOC was chosen, but not the instrument, with the aim of exploring this concept within a palliative care context.

SOC as a concept has been widely used in different contexts, but there are limited examples within the palliative stage of care. There are some studies within the cancer field, but they have mainly had a quantitative design using the SOC instrument or concerned patients in earlier stages of the disease (e.g. Boman et al., 1999; Delbar and Benor, 2001; Forsberg and Bjorvell, 1996). Nevertheless, Strang and Strang’s study stressed that the model is a relevant theory to understand relatives’ coping within palliative care (Strang and Strang, A. MILBERG AND P. STRANG

2001), and Andershed et al.’s study showed that relatives’ involvement in care of the dying was influenced by their sense of coherence (Andershed and Ternestedt, 1998).

The lack of studies using SOC within the palliative research field is a bit unexpected, because the theory of SOC seems of such high relevance within this context where there is no cure or prevention of the ultimate threat, that is death. In other words, the underlying goals within a pathogenically oriented health care service cannot be fulfilled in palliative care. Therefore, the salutogenic orientation based on the theory of SOC seems highly relevant within this context, and this has also been pointed out by others (Kallenberg, 2000; Palsson et al., 1994). Within a palliative context the goal is often to move the patients and families along the positive side of the health-disease continuum. As Antonovsky himself pointed out: ‘We are all terminal cases. And we all are, so long there is a breath of life in us, in some measure healthy’ (Antonovsky, 1987, p. 3). Therefore, the aim was to illuminate these three theoretical concepts within the context of informal carer’s situation in hospital-based palliative home care (HBHC).

Our primary intention was to study all three aspects of SOC. However, the process involved in the informal carer’s dealing with the concept of meaningfulness appeared to be very extensive, and also clearly related to spirituality and existentialism, and hence has been presented separately (Milberg and Strang, 2003). Therefore, the aim of this report is: to describe and interpret the content of comprehensibility and manageability of cancer patients’ informal carer in advanced palliative home care within Antonovsky’s salutogenic framework of SOC.

MATERIAL AND METHODS

Setting

The study was performed in a Swedish advanced palliative hospital-based home care setting. The multi-professional teams include doctors, nurses, auxiliary staff, occupational therapists, physiotherapists and social workers. Doctors, nurses and auxiliary staff are available night and day within half an hour when needed. Further, there is availability of a back-up ward in each of the teams (Beck-Fris and Strang, 1993; Rosenquist et al., 1999). The service provides full 24-h service in the patient’s own home, but uses the resources of the hospital as a basis. This means that e.g. aids normally used at hospitals are accessible for home care use, and e.g. infusions and transfusions are also possible at home. When needed, the service has its own rescue beds at the hospital.

The majority of the patients are terminally ill with cancer and have a mean survival of 50–60 days (SBU, 1999). Depending on the situation and actual needs, patients might have anything from infrequent home visits by nurse during stable periods, to several daily visits by the nurse, the doctor and other team members, when needed. The service is based on voluntariness. Severe substance abuse or certain psychiatric conditions such as acute psychoses are relative contraindications for this kind of care.

Subjects

Nineteen adult Swedish-speaking informal carers of cancer patients in three HBHC teams in one county of Sweden were included. The informal caregiver was identified by the patient (and noted in the medical record) as being the person primarily involved in the care of the patient in the home setting (Kristjanson et al., 1998). The informal carers were chosen according to maximum variation sampling technique, using background variables, as regards age, gender, education, relationship to patient, origin of patient’s malignancy, patient’s age and gender, in order to get as broad a range of the phenomenon as theoretically possible (Patton, 2002, p. 235). Interviews were performed and given preliminary analysis until saturation of the data was reached in the hermeneutic process (Kvale, 1996). Characteristics of the informants are presented in Table 1. Inclusion criteria were voluntariness, ability to communicate through Swedish and acceptance of tape-recording of the interviews.

Data collection

Cancer patients’ informal carers were asked by HBHC staff whether they were interested in participating in the study; and this was followed by a covering letter. Those who consented were phoned by the interviewer (the first author). Tape-recorded interviews (about 30–60 min) were
performed one \((N = 10)\), two \((N = 6)\) or three times \((N = 3)\) during the actual HBHC care and transcribed verbatim. The initial interview focused on the informant’s experience of being the informal carer of a patient referred to the HBHC program. Open-ended questions included ‘How is it to be an informal carer 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 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. The study was approved by the local research ethics committee.

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

<table>
<thead>
<tr>
<th>Description</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Women (n)</strong></td>
<td>10</td>
</tr>
<tr>
<td>Age in years (median (range))</td>
<td>67 (45–78)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Elementary (n)</td>
<td>13</td>
</tr>
<tr>
<td>High school (n)</td>
<td>3</td>
</tr>
<tr>
<td>University (n)</td>
<td>3</td>
</tr>
<tr>
<td><strong>Employed (n)</strong></td>
<td>7</td>
</tr>
<tr>
<td><strong>Relationship to patient</strong></td>
<td></td>
</tr>
<tr>
<td>Married or cohabit (n)</td>
<td>15</td>
</tr>
<tr>
<td>Child (n)</td>
<td>4</td>
</tr>
<tr>
<td><strong>Shared accommodation with patient (n)</strong></td>
<td>16</td>
</tr>
<tr>
<td>Patients’ age in years (median (range))</td>
<td>72 (57–86)</td>
</tr>
<tr>
<td>Patients’ gender (no of women)</td>
<td>11</td>
</tr>
<tr>
<td><strong>Origin of patient’s malignancy (n)</strong></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>4</td>
</tr>
<tr>
<td>Prostate</td>
<td>4</td>
</tr>
<tr>
<td>Bowel</td>
<td>2</td>
</tr>
<tr>
<td>Lung/thymus/mesothelial tissue</td>
<td>4</td>
</tr>
<tr>
<td>Ovary/pancreas/urinary bladder/lymphatic tissue</td>
<td>4</td>
</tr>
<tr>
<td>Uncertain</td>
<td>1</td>
</tr>
<tr>
<td><strong>Interviews</strong></td>
<td></td>
</tr>
<tr>
<td>Duration of patient in HBHC</td>
<td></td>
</tr>
<tr>
<td>1–3 months (n)</td>
<td>18</td>
</tr>
<tr>
<td>&gt; 3months (n)</td>
<td>12</td>
</tr>
</tbody>
</table>

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, p. 46). In addition, the applicability of hermeneutics within a medical context has also been illuminated recently (Mak and Elwyn, 2003; Svenaeus, 1999). Seven canons of a hermeneutic meaning interpretation (adapted and extended by Kvale, 1996; pp. 48–50; 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, i.e. 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 presuppositionless, and (7) every interpretation involves innovation and creativity.

The analysis was performed by the following steps: (1) The transcribed interviews were read through to obtain an overall picture (naive reading); (2) The interviews were then reread systematically, line by line, to identify significant text segments (meaning units) and develop matching codes—preliminary categories (decontextualisation). The predefined components (comprehensibility and manageability) within the chosen framework of SOC were applied to the text while coding, as preconceived phenomenon to be studied. The categories emerged inductively from the analysis of the interviews and were not preconceived; (3) The statements in each preliminary category were scrutinised and compared to find the central component; (4) The final categories were compared to avoid obvious overlap between them, and content descriptions were developed (recontextualisation).

Validity and reliability/trustworthiness

Several steps were taken to assure validity and reliability, in qualitative research literature often referred to as trustworthiness (Guba, 1981). The
interviews were conducted at a place according to the informal carer’s wishes, (at home in a room separate from the patient, at the geriatric outpatient clinic and in one case at the informal carer’s office), to ensure a milieu as confidence-inspiring as possible for the informants, thereby strengthen the ‘internal validity’ or credibility using Guba’s terms (Guba, 1981). Reliability aspects, that is aspects corresponding to dependability and confirmability using Guba’s terms, were considered by using Antonovsky’s explicit definitions of comprehensibility and manageability while coding the interviews (Guba, 1981; Antonovsky, 1987, pp. 16–19). In addition, five interviews were initially coded separately by both authors and there was good agreement concerning the concepts’ application to the text. 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. Involving several researchers (in this study two) might 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).

RESULTS

The results are presented in sections entitled ‘parts’ and ‘as a whole’. ‘Parts’ concern understanding of individual dimensions and resources important to informal carer at a rather concrete level. ‘As a whole’ regards the deeper meaning to the informal carer at a more abstract level. An overview of the results is presented in Figure 1. Although we have for pedagogical reasons chosen to present the results in a dichotomous way, e.g. togetherness vs isolation, they should be understood as continuous aspects of the informal carer’s experience, fluctuating in degree with time and context.

Comprehensibility

Parts. **Open information.** Open information involved multidimensional aspects of the patient’s health, such as comfort, treatment, and future. The patient, friends and health care staff contributed to open information in talks with the informal carer. The doctor seemed to have a central role in contributing such information, although other team members were also mentioned. Lack of open information originated in some cases in difficulties in getting in contact with
the staff, in other cases in the relationship with the patient. For example, when the patient did not want/did not have the strength to talk with the informal carer about the illness, although the informal carer had a need for information from the patient, the informal carer had to search for information from other sources, e.g. symbols.

Some days mother seems very well, but others she is very tired. I think she forces herself to do more than she should. So it is difficult to assess how ill she is, it is actually very difficult. For example yesterday evening, when she went to bed she had pain, so she took a painkiller. Then I thought, ‘Now it’s going to start [the deterioration]’ But today has been a good day. [whispering] No, it’s very difficult. (Informant E)

**Symbols.** Symbols concerned verbal and non-verbal clues that originated in talks or non-verbal interactions with the patient and health care staff. The informal carer saw or perceived pieces of information that were interpreted with a personal meaning. This resulted in a shift from a ‘neutral’ to either a more positive or more negative understanding, such as symbols of good health or impending death. Although the symbols could be negatively loaded, e.g. the patient losing weight as an indicator of impending death, this was a piece of symbolically loaded information that contributed to the informal carer’s understanding of the situation.

Symbols of death and deterioration were symptoms like pain, nausea, breathlessness or fatigue. ‘He has been panting much more lately. So I suspect it indicates such [deteriorating] development. Maybe.’ (Informant A). Another such symbol was HBHC as an organisation. For some informants HBHC symbolised death, and therefore when the informal carer was asked or informed about patient’s referral to HBHC he/she thought that death was approaching. In contrast, symbols indicating patient’s good health included physical aspects like round cheeks, good appetite or growing hair.

Also the topics the patient’s chose to talk about with the informal carer could constitute symbols of an approaching death to the informal carer. Examples of such symbolic topics were patient’s descriptions of cancer lumps in the body or explicit wishes concerning the funeral.

Informant: ‘She [mother] is talking a bit too much about the funeral and such things. I think it is quite burdening. But it is good for her, so we talk. But it is burdening.

Informant: ‘What makes it burdening to you?’

Informant: ‘I think [nervous laughter] it is because I do not want to hear about it [deep breath]. The ostrich, you know’ (Informant E)

Staff’s actions were also loaded with symbols. For example, when the HBHC staff had started up hormone replacement therapy for the patient, the informal carer interpreted the situation in the way that she is not likely to die soon.

**Basic life assumptions.** The informal carer not only relied on interpersonal (open and symbolic) information, he or she also used intrapersonal basic life assumptions in the search for understanding. One such underlying assumption was that some informal carers expected life to be fair. This had consequences for their feeling of comprehensibility, e.g. ‘I do not understand why my beloved is dying, because he is strong, competent and kind’ (Informant F). Another construct was that elderly people, as opposed to young, will experience illness and death, e.g. ‘It is understandable that my husband is dying because he is 78 years old’ (Informant H).

Basic life assumptions also involved the staff’s ability to know, e.g. what was going to happen with the patient. One such assumption was that doctors can predict the time left fairly well. This resulted in difficulties with comprehensibility when mis-prediction about the amount of time left for the patient occurred. The constructs interfered with the informal carer’s search for understanding of their situation. Religious beliefs were also integrated in their basic life assumptions and thereby affected the comprehensibility.

**Previous knowledge.** The informal carer’s previous knowledge, particularly about illness and dying, was also used as a dimension to create understanding. Prior experiences, such as caring for dying parents, could help the informal carer in understanding and managing the situation, e.g. that dying people may understate and mask their symptoms and say to friends that ‘it is not so bad’, despite rapid deterioration. Informal carers also used their own life experiences and mirrored the patient’s reactions against his/her own way of reacting, e.g. when being diagnosed with cancer.

As a whole. **Congruent inner reality/Chaos.** The informants struggled to understand and make meaning of the situation, a situation that was changing all the time as the patient’s condition deteriorated. The situation was sometimes difficult
because of confusing, conflicting sources of understanding and comprehensibility.

The cortisone makes one much more fit, ... She [the mother] looks very healthy. Too healthy, you see, nobody understands how ill she is, and neither do we, because of such things. The hair is coming back now, the cheeks are getting more round, she eats everything that comes in her way [laughter]. So, therefore we do not understand how serious it is.' (Informant E)

A deeper inner meaning of comprehensibility in such situations, that is comprehensibility at a higher abstraction level ('whole aspects'), concerned a notion of a congruent inner reality as opposed to an incongruent, chaotic one, which made the whole situation more comprehensible. ‘Congruent’ refers to the non-contradiction between the sources of comprehensibility, that is between the sources of comprehensibility at a lower abstraction level, such as open information, symbols, basic life assumptions and previous knowledge. ‘Inner reality’ emphasises the individuals’ deeper meanings of comprehensibility.

The deeper meaning of comprehensibility often concerned aspects of deterioration and death, such as when and how it was going to take place, and its consequences for the future. For example, if the patient was too tired to have meals together with the informal carer, this constituted a symbol indicating deterioration. This symbol was incorporated into the informal carer’s own reality and made her understand that she was going to have a future life not shared with her husband. In the following quotation, a daughter expressed comprehensibility regarding her mother’s approaching death. This was based on both open information from the staff and on symbols like decreased appetite, that created a congruent inner view of the situation.

Informant: It is very clear to me what is going on, the deterioration. I talk very openly with doctor X about that and mother takes part in these discussions too. We discuss these issues very well, I think, so it is clear to me what is going on and that we are approaching the terminal stage, rather soon, I think.
Interviewer: Why do you think so at this point?
Informant: I think so because of her blood tests, they have discovered new mets, she feels sick, has little appetite and her condition is deteriorating. (Informant G)

None of the informants expressed feelings of total chaos, possibly because they all seemed well informed and had had time to process the diagnosis and some of its consequences. However, some informal carers described an initial feeling of unreality and chaos during boundary situations in the disease trajectory, e.g. when the primary cancer diagnosis was disclosed or when tumour-specific treatment was stopped—‘It can’t be true’.

Manageability

Parts. Power. Power was described as a necessary resource, contributing to the feeling of manageability. It originated in the patient, the informal carer, and also in family and friends (other than the informant). The length of the illness influenced the perception of power. Some felt drained of power over time. Different dimension of power are presented below (examples within parenthesis): physical (patient having strong arms), functional (patient able to visit the toilet by herself), social (patient fighting for the sake of the family), psychological (informal carer feeling calm despite the deterioration), economical (family having fairly good economy) and existential (patient accepting her forthcoming death).

Competence. Competence concerned both that of the staff and the informal carer. Areas of competence dealt mainly with medicine, nursing and communication. Facing new demands for skills was difficult for some of the informal carers, while for others this role change went more smoothly.

Accessibility. This item concerned HBHC, but also the informal carer’s accessibility to family, friends, and patient. Positive aspects of accessibility included promptness, broad ‘opening hours’ (24 h a day), low threshold for accepted reasons for contacting (even trifles), and easy access (via telephone or visits).

Support. Both support directed to the informal carer and to the patient facilitated the informal carer’s manageability. Support came from the patient, family, friends, HBHC or other community service organisations, e.g. school or home help. Three main types of support were identified: emotional, practical and informational.

Emotional support concerned the support that was experienced just through social contact and communication with other people, not necessarily illness-related, e.g. meetings with the women’s sewing group. An emotionally supporting attitude was described as being positive, nice, paying
respect, caring, listening, placing the individual in the centre, looking into the eyes, being open/honest but not brutal. A non-supporting attitude meant lack of respect and warmth, an attitude of superiority, not listening or being too busy.

Practical and informational support dealt with various tasks related to everyday living (household, social activities) or the illness. An example was friends driving the informal carer to social activities and then visiting the patient meanwhile. Illness-related practical support dealt with aspects of medicine, nursing, and aids provided by health care staff. Informational support concerned information about different aspects, mainly provided by the health care staff.

I did not know how to fill up the car, my husband has always done that. Our friends are very supportive, they phone and ask if there is anything they can do. ... I do not think I would have managed this without them (Informant C).

As a whole

Togetherness/isolation. The informal carers were worried about things that could happen with the patient, especially during weekends and nights. The deeper meaning of manageability, that is at the whole, more abstract level, concerned feelings of togetherness as opposed to isolation, that made such situations more manageable despite the approaching death. Core aspects of togetherness/isolation concerned trust in the resources, shared responsibility, and being a resourceful contributing part.

A feeling of togetherness involved trust to oneself or in others that there would be enough resources if something happened. Resources such as children’s support, informal carer’s own and patient’s power, or staff’s competence, to manage the situation. Togetherness made the informal carers experience that they were not alone when fighting or managing the threatening situation. Instead both the relationship to the patient and to the health care staff could contribute in a positive way. The situation felt more manageable when the informal carer and the patient supported each other and when the responsibility for the patient was shared with the staff. For example, when the HBHC staff also talked to the patient about the need for changing accommodation (due to several falls), the informal carer felt relieved when the responsibility was shared, and this made the situation more manageable.

In contrast, a feeling of isolation left the informal carer alone with the whole responsibility for the patient—‘if something happens, I have to decide . . .’. In the following quotations, a wife expressed difficulties in manageability due to a feeling of isolation with overwhelming responsibility concerning the handling of a percutaneous endoscopic gastrostomy (PEG). This was opposed to the feeling of support and relief she felt when contacted by the HBHC team:

My husband was going to be discharged from the hospital [with a PEG], but I said I can’t take care of such things. But they said it was very easy to learn how to use it. ‘No’, I said, ‘I can’t take that responsibility’... Then the dietician came ‘It is so easy’, she said. I felt I was going to be ill, because I could not do this. (Sighs) And later on that afternoon I had diarrhoea. And was not feeling well and was terribly worried. ...

Then the palliative doctor came, and he was almost like an angel. He presented all the things the palliative home care team could offer. And then I felt that this was a support for us’. (Informant A)

Isolation could also concern being left outside, not regarded as a contributing resource in relation to the patient. For example, when the informal carer was not recognised by the health care staff as an important support for the patient in a burdening situation, this hampered a feeling of manageability. The informal carer could not contribute with a unique support that the patient needed and that nobody of the health care staff could give the patient, only the informal carer.

Informant: I wanted to be with him [husband] and I’m very disappointed ... I visited him every day, went directly to the hospital after my work had finished at noon, and stayed there until late night. He was going to get information about the results the next morning. I phoned him. We were hoping it was only the normal problems. But the doctor had already talked to him ... and then just left him ... The doctor could have waited until the afternoon, so I could have been there. ... It made me so angry, because they all knew that I came to my husband every afternoon. ... they could have phoned me and I would have come directly. This was so bad.’

Interviewer: What has this meant to you afterwards?

Informant: I do not know. I am angry and disappointed. I really think that I have tried to be a support at all times, and then when the final result came. It is so unnecessary. I know they have done the
same to several others. I do not understand why they act in this way. (Informant T)

Interactions with HBHC had for a few of the informal carers contributed to a feeling of isolation. These informal carers had felt pressured by the staff, who openly or symbolically expressed home as the preferred place of care, while the informal carer was very isolated with his or her fear of situations of acute deterioration. Other reasons for a feeling of isolation and burdening responsibility were when the patient only accepted help from the informal carer, or when the patient did not request help but in reality was totally dependent on the informal carer’s awareness of his or her situation.

**DISCUSSION**

Coping studies in the setting of palliative care have mainly had either a stress perspective or have been conducted without an explicit theoretical frame, despite there being a mature research area with several well-established salutogenic theories. This study provides a content description of comprehensibility and manageability in a specific context, namely that of informal carers of dying cancer patients in advanced palliative home care. The findings showed that although the situation was stressful and burdening for the informal carer, the ability to achieve positive states of mind that facilitated comprehensibility and manageability was not totally hampered. Comprehensibility and manageability was facilitated by open information, previous knowledge, power, support, competence, and accessibility, and these findings are all supported by other studies in palliative home care settings (Brown et al., 1990; Davies et al., 1990; Grbich et al., 2001; Hull, 1991, 1992; Longman et al., 1992; Skorupka and Bohnet, 1982; Steele and Fitch, 1996a, b), and also by studies conducted in general palliative care contexts (Davies et al., 1994; Hardwick and Lawson, 1995; Hull, 1989; Kinsella et al., 2000; Kristjanson, 1986; McCorkle and Pascareta, 2001; Rose, 1999; Sales et al., 1992). The effects of patient’s age and beliefs about the fairness and justice of the world on the informal carer’s feeling of comprehensibility are also supported by previous research (i.e. ‘young people do not die’, ‘the world is fair and just’) (Hinton, 1999; Park and Folkman, 1997; Seale and Addington-Hall, 1995).

However, the present study revealed aspects concerning informal carer’s perception of comprehensibility and manageability that have not been much illuminated in earlier palliative literature and that seem important for the clinical situation, namely the significance of symbols, a congruent inner reality and a feeling of togetherness.

**Methodological considerations**

In the interviews, informants did not make a clear separation between their experiences before the referral and during advanced palliative home care, although they were asked about their experience during the latter. 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. In addition, it is important to remember that at the time of the interview both experiences (before as well as after referral to a palliative home care service) were part of the total experience as a informal carer, and a separation would be artificial.

**Comprehensibility—more than traditional information-giving**

One source of comprehensibility in our results was open information, and such information has previously proved to be important in relation to cancer and informal carers, both as a specific coping strategy (information-seeking) and as part of health care staff interventions (information-giving) (Hardwick and Lawson, 1995; Hull, 1989; McPherson et al., 2001; Rose, 1999). Families want access to liberal amounts of information. Still families report difficulty obtaining enough information (Hileman and Lackey, 1990; Kristjanson and Ashcroft, 1994; Lecouturier et al., 1999).

The interviews also revealed that when the informal carer’s searched for comprehensibility, they used symbols as an important source of comprehensibility. Symbols are central components within a symbolic interactionist perspective (Charon, 1995), and also within psychoanalytic theory (Jung, 1990). Jung made the following description: ‘What we call a symbol is a term, a name, or even a picture that may be familiar in daily
life, yet that possesses specific connotations in addition to its conventional and obvious meaning:’ (Jung, 1990, p. 20). This description has clear similarities with the concept of symbols that emerged in our study.

There has been little discussion of symbols within the palliative context, although there are clear support for the general idea in relation to death and dying, e.g. (Davies et al., 1990; Friedrichsen et al., 2002; Lobchuk and Kristjanson, 1997; Schaverien, 2002). Symbols such as pain relate to what Lobchuk and Kristjanson labelled ‘cues’. Cues, e.g. impaired functioning, as sources for assessment of patient’s symptom distress were supported in our study, and also by others giving practical advice about communication within palliative care (Oliviere et al., 1998, p. 105; Faulkner and Maguire, 1994, p. 46). In addition, the present study showed that symbols were relevant not only in such assessments, but also when making meaning of the situation at a deeper level in relation to forthcoming death.

This additional impact of the patient-informal carer interaction is supported in previous literature (Davies et al., 1990; Lobchuk and Stymeist, 1999). Davies et al. showed that decline in the patient’s physical condition was a signal to the families that the end was approaching. Such deeper features of comprehensibility were conceptualised in the present study as congruence within one’s own inner reality. There is scarce literature concerning the actual deeper meaning of comprehensibility—to informal carer in palliative care as well in general. Nevertheless, there is support for our findings in similar studies (Park and Folkman, 1997).

The expanded view of comprehensibility (as presented here) has similarities with the development within theory of learning. Previously, pedagogical theory focused on information-giving with the risk of one-way communication. However, there has been a change from such a quantitative orientation to a qualitative one, stressing the individual’s construction of meaning and the impact of the sociocultural context (Säljö, 2000).

Our findings have clear similarities to the advice that commonly is given regarding communication and information-giving to families and patients within cancer care (Buckman, 1998; Faulkner, 1998; Faulkner and Maguire, 1994). Moreover, our study contributes with two additional explanations why informal carers are dissatisfied: (1) comprehensibility rests on more sources than traditional information-giving (i.e. what is labelled ‘open information’ in this study), sources such as symbols, basic life assumptions and previous knowledge; and (2) comprehensibility concerns also a deeper level to the individual and there is a need to expand the concept of information-giving also to include such deeper meanings of comprehensibility.

In a clinical situation the practitioner can chose to respond to questions in a traditional information-giving way (in this study labelled open information) and some of the informal carers will probably be satisfied by this. However, according to this study such questions may sometimes concern also other sources of comprehensibility or involve a deeper level of understanding. This means that in order to support the informal carer, it seems important for the practitioner to be aware of the possibility of other meanings with such questions. For example, the question ‘My wife is in pain, why?’ may also mean ‘My wife is in pain, why? Is she dying?’, (pain—a symbol of death), or ‘My wife is in pain, why? Is she dying, despite the fact that she is only 57 years old?’ (basic life assumptions: life is fair, but this is not fair). In addition, the question ‘My wife is in pain, why?’ could also be a signal of an incongruent inner reality such as ‘My wife is in pain, why? She looks so healthy and has a good appetite, I do not understand’; (incongruent inner reality: she looks healthy but pain can be malignant, what should I believe?)

The challenge for the practitioner is to acquire enough knowledge about the individual’s basic life assumptions, previous knowledge and inner reality to be able to balance the information-giving (symbolic as well as open) so the informal carer can incorporate and construct a ‘congruent inner reality’. Attention to the great impact of symbols—such as symbolic words (Friedrichsen et al., 2002) patient’s and professional carers’ behaviour, seem important. If these aspects are not incorporated in our view of how informal carers’ make meaning of their situation, there seems to be a risk that traditional information-giving might hamper comprehensibility and instead contribute to an inner chaos.

Manageability—also a more abstract level to aim for

Previous research has shown that, compared to conventional care, specialist teams in palliative
care improve satisfaction, deal with more patient and family needs, improve patients’ likelihood of dying where they wished to, and reduce the number of inpatient hospital days (Hearn and Higginson, 1998). From a SOC perspective one could say that specialist palliative care teams seem to improve the families’ manageability at home.

In this study, power, competence, accessibility and support were all important aspects contributing to the informal carers’ feeling of manageability. As already pointed out, these aspects are well-supported in previous palliative literature. Hypothetically, such resources may explain the mentioned differences in manageability. Although the present study is not a comparison between informal carers of specialist palliative home care and conventional care, it illuminated what seems as important aspects of the participants’ feeling of manageability in specialist palliative home care, namely togetherness and isolation (in addition to the more concrete aspects already presented above). Such abstract levels of manageability seem important in the understanding of the concept beyond a surface level within specialist palliative care.

The informal carers contrasted feelings of togetherness with descriptions of isolation, when they felt abandoned and alone with the responsibility taking care of the patient despite lack of competence. Existential isolation is a basic concept within existentialism. Psychiatrist and existential psychotherapist Irwin Yalom makes a distinction between existential intrapersonal isolation and interpersonal isolation/aloneness (Yalom, 1980). The first concept referring to ‘an unbridgeable gulf between oneself and any other being despite the most gratifying engagement with other individuals and despite consummate self-knowledge and integration’ (p. 355). The second one, describing ‘isolation from other individuals as a function of many factors: geographic isolation, the lack of appropriate social skills, heavily conflicted feelings about intimacy or personality style … that precludes gratifying social interaction’ (Yalom, 1980, p. 353). The feeling of isolation illuminated by this study seems to relate to the existential kind of isolation.

Isolation also seems as a central concept within palliative care, and is mentioned for example by Saunders (1984) and Kearney (2000, p. 153). Saunders suggested that ‘isolation … accentuates all sufferings’ (Saunders, 1984). Our findings suggests that a relationship conceptualised as ‘togetherness’ with the patient or the staff could reduce such burdening isolation. The concept of togetherness concerns a deeper meaning of manageability, and relates to already applied concepts in the context of palliative care or in other care contexts, namely: sharing caring (Milberg et al., 2003), connecting (O’Berle and Davies, 1992) and involvement in the light (Andershed and Ternestedt, 1998) and patient-centredness (Mead and Bower, 2000).

The possibility of supporting salutogenic relationships in relation to isolation seems as an important challenge for the practitioner. As Kearney expressed it: ‘The observation is frequently made that the person in suffering no longer felt so isolated. Although they may speak of having still felt alone in their experience, as a result of the meeting with the other the barrier of isolation was broken and they were better able to live with this sense of existential aloneness, which seems to be an integral characteristic of the human experience of suffering’ (Kearney, 2000, p. 153). If not salutogenic aspects are paid attention to, important and possible clinical goals may be missed, such as informal carers having a feeling of togetherness.

Future research

The findings raise several issues important to practitioners and for future research. What are the actual processes involved, as opposed to the content illuminated in this manuscript, in facilitating and impairing comprehensibility and manageability? How does one increase awareness and competence among staff concerning support to informal carer in their dealing with comprehensibility or manageability? Understanding such issues as well as effective interventions seem important for both the informal carer and the patient in palliative care.

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