The perspectives of bereaved family members on their experiences of support in palliative care

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Abstract

Aim: To explore family members’ supportive interactions in palliative care and the emotional experiences that they associate with these interactions. Methods: Qualitative individual interviews were performed with bereaved family members recruited from an urban palliative care service in Sweden. The interviews were analysed using inductive qualitative content analysis. Results: Five categories of supportive interactions with staff members were linked with emotional consequences: informational support, supportive encounters, professional focus of staff, a supportive environment, and bereavement support. Having a dialogue with family members nurtured certainty and security, supportive encounters gave a warm and comforting feeling, and bereavement support contributed to feelings of strength. Environmental factors contributed to dignity. Conclusion: Supportive interactions with staff and within a home-like environment help to build resilience if tailored to the family member’s own needs. Key words: Bereavement • Family • Grief • Loss • Palliative care • Social support • Interviews

To be close to someone who is dying is a major challenge in life. The palliative model of care puts the family in the spotlight as the central unit of care. Palliative care professionals, in addition to treating and communicating with a terminally ill patient, need to understand the family structure, and they need to have skills in family communication (Fineberg, 2010). The palliative period puts a lot of different pressures on family members: changes in responsibilities, changes in social life, and uncertainty faced with the unknown, and so help and support with these issues may be needed (Stenberg et al, 2012). Bereavement also presents considerable challenges around experiences of loss and life transition (Parkes, 1999; Machin, 2007).

Supportive interventions have been found to alleviate suffering and strengthen the social network (Kristjanson and Aoun, 2004; Milberg et al, 2008). It is also known from the social support literature that a person’s coping resources can be mobilised and new coping skills made available through social support (Reblin and Uchino, 2008). In the crisis of bereavement, recipients express their experiences of supportive interactions in terms of their emotional value (Olsson, 1997). However, there is no strong evidence regarding which specific types of support from professionals may be particularly helpful (Candy et al, 2011).

Family members’ experiences of social support from professionals are increasingly being reported in research (Teno et al, 2004; Andershed, 2006; Mehta et al, 2009). However, few studies in palliative care link specific experiences of social support received from professionals with emotions experienced by the family members (Funk et al, 2009; Candy et al, 2011).

Aim

The aim of the present study was to explore the supportive interactions that family members experience in palliative care and the emotions that they associate with these interactions.

Methods

This exploratory qualitative study used retrospective family member accounts of interactions with palliative care professionals in end-of-life care. One of the strengths of a qualitative research design is that it allows for nuanced descriptions, which are valuable when searching for new information (Kvåle, 1996).

Setting

The study was conducted in an urban Swedish palliative care service with 40 beds and a home care unit. The service had a structured professional social support programme that aimed to improve the mental health and quality of life of family members. Within the programme all families were offered basic support, meaning the establishment of contact between the staff and the family, which included family meetings, oral and written information, and support before and
at the time of the death. A letter of condolence was also sent 3 weeks afterwards. Specialised support was given to families for whom the death was sudden, unexpected, or difficult or when there were children or young adults in the family. A doctor was responsible for contacting the bereaved family member within 1–4 days to give medical information, to follow-up, and to answer any questions. A social worker was responsible for supporting and counselling families with children or with problems in their social relationships or life situation. The specialised support could also mean extra support from nurses, a priest, or an external referral if needed, e.g. to psychiatric care. A support group was offered to bereaved young adults (16–28 years of age).

Participants
The sample frame of the study consisted of family members participating in the support programme over a period of 2 months (family members of 60 patients). The patients' ‘key relative’, i.e. the person identified in the medical records as the one most affected by the death of the patient, was selected for participation. If no key relative was identified, the next of kin first noted in the patient’s medical record was approached. Strategic sampling of 30 key relatives over 18 years of age was carried out in order to reach family members with experiences of specialised as well as basic support. According to the support programme all key relatives would have received basic support and 20 of the 30 would have received some kind of specialised support.

About half a year after the patient’s death, the interviewer sent a letter of information and a week later phoned the key person; 13 partners, 8 adult children, and 4 other family members agreed to participate. Of these, 12 were female and 13 male. The five family members who declined to participate generally gave several reasons, including that it was too painful to talk about their experiences \((n=3)\), other traumatic events had occurred \((n=1)\), they were disappointed with the palliative care \((n=2)\), they lived outside Sweden \((n=1)\), and lack of time \((n=2)\).

All of the patients whose relative took part died from cancer. The patients’ mean age at the time of death was 65, and their age range was 39–88.

Interviews
Individual qualitative interviews were performed a mean of 8 months after the loss \((range \text{ 6–9 months})\). This time was deemed not too close to the experience of loss or to any upcoming ‘anniversary reaction’. A semi-structured interview guide was developed and piloted by the authors. It focused on experiences of supportive interactions in the palliative care unit and on the family members’ reactions to these (for examples of questions, see Box 1). The interview guide allowed for sequential variation in the questions, and the family members were encouraged to talk freely \((Kvale, 1996)\). The interviewers were a social worker \((TL)\) and an experienced nurse. Both had experience of palliative care and neither worked at the unit. Twenty three interviews took place in a research facility close to the palliative care location, and one took place in the home and one in the workplace of the interviewee. The interviews lasted about 1–1.5 hours and were audio-recorded.

Analyses
All interviews were transcribed verbatim and at first the different supportive measures of the programme were identified. Thereafter an inductive qualitative content analysis was used according to Elo and Kyngäs \((2008)\). All the interview data was read through several times by the first author and statements about supportive interactions and emotional experiences were then excerpted. The next steps of the analysis were performed by TL and MO. Open coding was used to further condense the text. The codes were grouped according to conceptual relatedness and organised into subcategories and categories. The analysis process went back and forth between the initial transcripts and the categories in order to validate the findings in light of the interview contexts. In an abstraction phase, categories of emotional experiences were connected to the categories of support that the family member was referring to. In order to enhance the trustworthiness of the results, the analyses were carried out by the two researchers, both individually and in joint sessions, to include reflectiveness and to reach agreement in categorisations \((Tong \text{ et al, 2007})\).

Box 1. Example questions from the interview guide

- Please, tell me about [the person who died]; his/her disease and last days of life. How did you experience this period? What about the treatment period?
- Please, tell me about your (and other family members’) interactions with members of the staff during the days in the hospice. What in these experiences was positive? Negative? What kind of impact do you think this has had?
- Now, after half a year, if you look back, I have some questions: what did [the person’s] death mean to you? What made you cope well with this experience? What about your current views for the future?
- Did you receive some kind of support from [the palliative unit] after the death of [the family member]? In what form? (Ask for details.) Has this relationship ended?
The study was approved by the Regional Ethical Review Board (registration number 2005/1355-31). The participants were informed of the purpose of the study and assured of anonymity. Support was available to those assessed as being in need.

**Results**

The participants reported about basic as well as specialised support. A majority (18/25) had experienced a family meeting and 13/25 had received a letter of condolence. Contact with the social worker was reported by seven participants, all of whom were stratified as having problematic circumstances or children in the family, making them eligible for specialised support.

The inductive analyses resulted in five categories of supportive interactions: informational support, supportive encounters with staff, the professional focus of staff, a supportive environment, and bereavement support. They also resulted in six emotional consequences: a sense of certainty; a sense of security; a feeling of warmth and comfort; a sense of value, dignity, and harmony; and experiences of strength. At a second ‘round’ of analysis each category of interaction could be paired with a certain emotional consequence (Table 1). These inductively created category pairs are used as subheadings below.

### Informational support: feelings of certainty and security

All of the interviews demonstrated that receiving information was interpreted as a supportive interaction. Honest and straightforward information, especially when offered in a dialogue with the family member, left no need for questions and gave answers to the person’s worries, even though there could still be a difficult time close to the loved one’s death. Being informed gave a sense of certainty and security.

‘... and, very importantly, then this clear message came, yes—the same nurse also gave me directions ... Because, you felt, kind of dizzy, and you didn’t quite understand what was going on, why it was like this.’ (Widow)

The information needed to be repeated in order to maintain this feeling of certainty.

‘I don’t think we miss ... so to speak general information, however ... the question is if they should have had more short process meetings, where you just learn “Our assessment of her condition is that ....”’ (Widower)

Information from booklets also helped the family members to gain some feeling of security.

‘... sometimes it is easier to read than to have it explained to you. ‘Cos you might start thinking “Is it really true what she says?” But, like this, in a booklet—you feel that this is true.’ (Daughter)

Criticism regarding information came about a lack of openness. This was even interpreted as an implicit message, that there was no reason to bother about how the family member would manage the stressful situation. The patient was going to die anyway, and the family member was left with a feeling of anxiety and despair.

‘... I was frightened, I sort of understood “Oh well, he’s not getting any nourishment, he’s not getting any water. Are you just going to lie there and die like that?”’ (Daughter)

### Experiences of supportive encounters: a warm and comforting feeling

The second category of support comprised statements about the quality of encounters taking place with staff members. Most family members felt that the patient and they were in good hands. The period in the hospice was contrasted with other more negative experiences from hospital wards.

‘... and he came in to the emergency ward at [hospital] and that’s a hospital which I wouldn’t recommend to any human being ... It was like heaven when he came here. Nice people ... and here they were completely wonderful. There was one nurse up there [name of the nurse],

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**Table 1. Categories of support and positive emotions connected to them**

<table>
<thead>
<tr>
<th>Supportive interactions</th>
<th>Emotional experiences connected to interactions</th>
</tr>
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<tbody>
<tr>
<td>Kind of information (clarity, honest dialogue)</td>
<td>Sense of certainty and security</td>
</tr>
<tr>
<td>Quality of encounters with staff (empathy, availability, flexibility)</td>
<td>Warmth and comfort</td>
</tr>
<tr>
<td>Professional focus of staff (patient and family orientation)</td>
<td>Sense of value</td>
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<tr>
<td>Environmental aspects</td>
<td>Dignity and harmony</td>
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<tr>
<td>Bereavement support</td>
<td>Certainty and strength</td>
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who was like a mum for the two of us ...’  
(Widow)

The terms ‘warmth’ and ‘comfort’ were used when talking about encounters with staff members. These feelings were aroused when doctors and/or nurses showed empathy and flexibility and took the time to sit down and talk to the family members.

‘You really noticed, there were people, who ... also talked in a way that ... that let you know that they understood how difficult it was ...’  
(Relative)

Warmth and comfort were also felt when a dialogue about preferences regarding the moment of death had taken place, and when a staff member was present when someone was badly needed.

‘There was this nurse ... We had met him the night before, and he was very quiet and comforting ... we were allowed to stay for as long as we wanted ...’  
(Widow)

Although many family members felt a sense of warmth, there were exceptions, and the atmosphere in such encounters was described as, for example, ‘hurried’. When the family member felt that their anxiety or grief had been ignored, this was interpreted as a lack of warmth.

‘“Now we have to ask you to hurry up because we cannot have her lying here, so you have to call a funeral agency right away ...” when we were about to leave after mum had died. So you got really stressed and started to chase that ... You almost got pissed off. Isn’t it enough that we can have our grief for a while, and then take care of that?’  
(Son)

The professional focus of staff: contributed to a sense of value
A specific support category was the family member’s interpretation of staff members’ dedication and focus. This category included ways of caring for the patient as well as supporting other family members. When the focus was positively evaluated, this contributed to the family member’s feelings of value and self-esteem.

‘They asked if you had had anything to eat ... like coming home to a mum or a grandma, so that was really good.’  
(Widower)

It was a source of satisfaction to see how staff members assisted the patient when necessary.

‘I thought it was very positive, when it came to pain relief ... she [the nurse] said, “I don’t really know what to give him instead, but I’ll think something out ...”’  
(Widow)

After a while she came back and said, “Now I’ve thought about this medication...” It was not that they had a standard procedure to do this or that, instead it was a friendly procedure ... and just this that we family members were counted in, that they were there for us as well, I thought that was really nice.’  
(Widow)

Similarly, if problems and needs were not picked up, the lack of patient-centredness gave rise to feelings of degrading the value of the loved one and/or family members.

‘There was no touching ... Mother’s friends asked about giving her some massage, or something like that. “No, there’s no need, because she has an air bed.” But we thought, this can’t make up for human touch.’  
(Daughter)

A supportive environment: signalling dignity and harmony
The general atmosphere as well as the physical environment, the size of patient rooms, food for family members, a piano to play on, nice furniture, beautiful colours, and art contributed to feelings of support.

‘The environment was very nice. She had an excellent room ... That you could come and go as you wished. Ehhh, the room was so big that it was possible to have several people there ... There are pretty big general areas too. We arranged small dinners and parties, well this was an exaggeration, but it was in that direction.’  
(Widower)

Words like dignity and harmony were used when the family members talked about the environment facilitating the expression of their grief.

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(Widower)

However, this harmony was experienced as too directed, as though anxiety was not tolerated and there was only one proper way of reacting to a loss.

‘You can feel it in the system ... It feels like there is a pattern for how you should die. That you preferably should fit into. And if it’s like you’re too worried, or about to die or something else you medicate away most things.’  
(Widower)
Bereavement support: important for a sense of certainty and strength

Supportive interactions after the loved one’s death were talked about as a separate ‘chapter’. Supportive dialogues strengthened the family members and offered assurance that they had done nothing wrong.

‘The physician … she said that “This was so widespread, it has been there for a long time and if you had reacted and it would have been discovered earlier it might have been worse because the outcome would have been the same … she would just have had to live with the knowledge that it was going to end for a longer period. And it might have destroyed her quality of life during this period.” So the conclusion of her reasoning was that it was optimal the way it went, and I have to say it felt really good … because it was like this burden of guilt that I was working with, was being lifted from me.’ (Widower)

During this period, letters of condolence gave a sense of strength. Follow-up calls were appreciated even more, especially when a doctor phoned.

‘He still cares about me. Fourteen days after my wife died, the chief physician calls and cares about me. Wow! I was overwhelmed.’ (Widower)

However, if follow-up calls or letters were not received in spite of promises, this was a negative experience and evoked uncertainty and even feelings of guilt.

‘Well, I’d have preferred this [phone call] pretty soon afterwards, I think. I’ve been wondering about what I did wrong, since I couldn’t handle this. I feel like I did something wrong.’ (Widower)

From encounters with the social worker and the priest, family members learned how to understand their own reactions and could get affirmation. For some family members the support group for bereaved young adults was the most positive experience of all the supportive measures taken in the palliative care setting.

‘Now afterwards, I’m most satisfied for the girls, actually. The fact that this support group was offered and that they experienced that they weren’t alone in this situation.’ (Widow)

Summary
In summary, feedback from family members about end-of-life care in a setting using a structured support programme pointed to the importance of clear information and of supportive encounters during the late palliative phase as well as in bereavement, in addition to the impact of good quality patient care and a home-like environment. Words used by the family members in retrospect included a sense of certainty and security, comfort, value, dignity, and strength. When the programme failed, experiences of anxiety and despair, devaluation, uncertainty, and guilt were reported.

Discussion
In this study, bereaved family members shed light on the connection between the social support received from professionals and their emotional experiences of these interactions. The method was chosen in order to capture the essence of the family members’ experiences. Despite the lack of ‘distinct’ follow-up contacts experienced by many, most family members experienced receiving clear information, an honest and open dialogue, and supportive encounters, as well as a supportive climate. Several positive emotions found in connection with social support from staff members were also included in the descriptions of balanced or resilient grief responses (Machin, 2007), e.g. security, certainty, and a sense of value and strength. The results indicate that the grief process can be facilitated by end-of-life support in palliative care, and the authors suggest that these positive emotions also have the potential to enhance wellbeing and resilience in the bereavement period.

The experiences of supportive interactions may well be understood as reciprocal communication and interaction between two parties (Finfgeld-Connet, 2005; Sarason and Sarason, 2012). The experiences also fell into the functional categories of social support mentioned by Langford et al (1997); informational and emotional support had a prominent place in the interviews.

The impact of informational support as a means of achieving a sense of certainty and security in difficult times found in this study is in line with Friedrichsen (2003), who showed that informational support helps family members to understand the situation and mentally prepare themselves. The findings are also in accordance with those of Hebert et al (2008), who conducted a study of questions that are important to family members in preparing for the death of a loved one. Unanswered questions about the disease and the treatment could lead to lasting uncertainty. Parkes (1999) suggested that unsatisfied informational needs may occur because such interactions are not offered, are
offered but not appreciated as supportive, or do not match the needs of the family member at the time. As described by Benkel et al (2010), support from professionals needs to be tailored to the recipient’s coping strategies.

Within the theme ‘professional focus of staff’, the present study found that a sense of less value was connected to poor patient care. This was also shown by Milberg et al (2004), who found that feelings of powerlessness and helplessness might be aggravated by the patient's suffering.

The finding that emotional comfort and dignity are enhanced when the hospital environment feels home-like is similar to the findings of Williams et al (2008), who concluded that the hospital environment can be therapeutic and promote personal control and emotional comfort. However, the findings warn against standardising the emotional climate. Instead, it needs to be tailored and tuned to the family member’s own status and needs, which was most evident with young adults.

The importance of bereavement support established by, for example, Payne and Lloyd-Williams (2003) and Milberg et al (2008) was also emphasised in this study. It was crucial that the follow-up that family members had been prepared for was actually delivered. As also found by Linderholm and Friedrichsen (2010) in a study on family members’ caregiving role and support in and after the end of life, broken promises provoke an overwhelming emotional reaction.

In Sweden, more and more attention is being paid to increasing psychological ill-health among young adults (The Swedish National Board for Youth Affairs, 2009), and research and clinical best practice are warranted for this age group in order to prevent affective disorders and premature death (Rostila and Saarela, 2011). In the present study the support groups for young adults were specifically mentioned as extremely important for a family. An evaluative, prospective study by the authors’ research group focusing on support groups for bereaved young adults is ongoing.

**Strengths and limitations**

This was an exploratory qualitative study that did not aim to make generalisations. The strategic sampling aimed to obtain knowledge concerning the experiences of different supportive interactions with professionals. To increase the trustworthiness of the results, the authors, who had different scientific backgrounds, repeatedly discussed the whole study, from the planning stage to the analysis of data. The study has informed the palliative care setting about the programme recipients’ emotional experiences of support. Transferability is indicated by the similarities with findings of other studies on family members in palliative care and bereavement. Descriptions of the context and the family members and the use of quotes will hopefully allow the reader to further decide about the transferability of the findings (Tong et al, 2007).

**Conclusions**

The emotional consequences of a supportive interaction with staff members demonstrated in this study, just as in a recent review (Candy et al, 2011), are found to be even more important than the interaction itself. The family members’ own assessments of the social support received therefore need to be the focus of palliative care. The study reveals some crucial points for building resilience in bereaved family members after a loss: forming a dialogue with a person in an acute phase of crisis and thus nurturing a sense of security, and contributing to certainty and strength in bereavement using encounters tailored to the family member’s own needs.

Targeting intervention for young adults is important, and also has the potential to facilitate resilience. As bereaved family members seldom take the initiative to make contact (Olsson, 1997; Sand and Strang, 2006), the care provider has to reflect on which kind of bereavement support to offer. Feedback from bereaved family members is needed to improve palliative cancer care (Miyanishi et al, 2008) and such research is continuously being asked for (Candy et al, 2011; Hudson et al, 2011). [IPS]

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