A support group programme for relatives during the late palliative phase

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Abstract
This study describes an intervention where relatives were invited to take part in a support group programme during the late palliative phase of their family member. The purpose was to describe their experiences of the support group programme and the subsequent impact on their lives as relatives of a terminally ill person. Qualitative interviews were chosen as the data collection method. The analysis was inspired by the phenomenological method as described by Giorgi (1989). The relatives’ experiences were categorised into six key constituents: confirmation; insight into the gravity of the illness; sense of belonging created by similar experiences; participation in the care system; being able to rest; and strength to provide support for the patient. These six constituents resulted in a sense of safety in relation to the patient, the illness, the nursing staff and the care unit. The study’s findings show that interventions of this kind may be integral to the relatives’ ability to handle their situation when caring for a terminally ill family member.

Patiens receiving end-of-life care often have a great need for support and practical assistance from their relatives. Furthermore, according to Broback and Bertero (2003), relatives often wish to care for their sick family member, which, in turn, can give a sense of being able to reciprocate the love and care they received earlier in life from the person who is now terminally ill. Relatives may feel that it is an opportunity to show that they care, although this can also be a burden. Therefore, the role of relatives is ambiguous; they are both the givers of care as well as being dependent upon receiving support themselves (Andershed, 1999; 2006).

There are many difficulties in supporting a close relative in the final stages of life and a relative can become exhausted merely from living with the responsibility involved (Broback and Bertero, 2003). Studies show that relatives can become even more stressed than the patient. Stress can affect the ability of relatives to support and care for the sick or dying person (Weitzner and McMillan, 1999). This situation has proved to have negative consequences for the relatives, such as tiredness and depression, sleep disturbances, lack of personal time, loneliness, isolation, anxiety, worry and feelings of guilt (Grbich et al, 2001; Andershed, 2006). Positive experiences may emerge in the context of regarding the remaining time with the patient as a gift and as an opportunity to communicate and show love through caring (Grbich et al, 2001; Aranda and Hayman-White, 2001).

A number of studies have identified a need for information and communication for relatives who are close to someone near death (Andershed, 1998; Andershed and Ternestedt, 1999; Eriksson and Lauri, 2000; Wilkes et al, 2000; Mok et al 2001; Hudson et al 2002; Albinsson and Strang, 2003; Broback and Bertero, 2003; Proot et al 2003). Hudson et al (2002) showed that information can fill a number of needs for relatives, such as easing feelings of loneliness and vulnerability and also strengthening relatives’ sense of control. Andershed (1998) found that information (to know) could be a prerequisite when relatives are to choose in which way to be involved in terminal care. Studies also report on relatives’ needs for emotional support (Eriksson and Lauri, 2000; Chambers et al, 2001; Mok et al, 2002; Broback and Bertero, 2003). It may be equally important for both patients and relatives to be allowed to occupy a central position in terminal care and receive attention and affirmation from the care team (Milberg et al, 2003). These studies also highlight a need among relatives to learn practical care (Andershed and Ternestedt, 1999; 2001; Broback and Bertero, 2003; Milberg et al, 2004).

Various countries have specially developed support programmes organised by
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‘The aims of the meetings are to offer relatives a chance to meet others in a similar situation, obtain information and discuss their situation with professionals’

the health services or voluntary organisations in order to support relatives in cancer care. Some programmes address both relatives and patients (Todd et al, 2000; Northhouse et al, 2002), while others address only relatives (Cawely et al, 1998; Pasacreta et al, 2000). The aim of support programmes has been to assist people in managing the illness situation through training and increased support. The relatively small numbers of programmes that have been evaluated have obtained good results. The participants have received a high degree of support and information plus the opportunity to discuss the difficulties they have encountered, which has led to increased knowledge and wellbeing. Relatives and patients were strengthened by the programme and this led to increased opportunities for successfully managing the situation (Grahn and Danielson, 1996; Pasacreta et al, 2000; Roberts et al, 2002; Northhouse et al, 2002; Witkowski and Carlsson, 2004). Despite these positive experiences, there are few interventions aimed at relatives in palliative care (Harding and Higginson, 2003; Andershed, 2006).

Aim of the support programme

The purpose of this study was to describe how relatives of terminally ill and dying people experienced being participants in the support group programme and what impact the support group had on their lives in the context of being a relative to a person in the last palliative phase.

Setting

The study was carried out at a palliative care unit in Stockholm, Sweden. The unit is a specialist palliative care service, which is provided for dying patients and their families with moderate-to-high complexity of palliative care needs. The unit delivers a 24-hour service and consists of a multiprofessional team. The patients are in the late palliative phase with an average life expectancy of three months. The unit consists of a home nursing section integrated with an inpatient ward, which means that the same care team looks after patients whether they are at home or on the ward.

Support programme

At this unit a support programme has been developed where the relatives are invited to take part in a support group during the late palliative phase. The group meets on the ward for an hour and a half a week for six weeks, and each meeting has a special theme with an ‘expert’ invited by the palliative team. The aims of the meetings are to offer relatives a chance to meet others in a similar situation, obtain information and discuss their situation with professionals (Table 1). The themes are chosen on the basis of a comprehensive study of relevant scientific literature, the experience of nurses in palliative care and a review of the needs of relatives at the unit. Much of the emphasis is on the relatives and their wellbeing, and on the opportunity to handle the illness situation. An important factor in the meetings is an open-minded approach with regard to the relatives’ needs. Two nurses from the palliative team act as group leaders and participate in each meeting (Table 2). The participants are offered tea, coffee and sandwiches at each meeting.

Method

In order to describe the family members’ experience of participating in the support group programme, a phenomenological method was chosen. Phenomenology aims to describe the world as people experience it and to seek out patterns with the purpose of catching the essence of the studied phenomena. Phenomena can be understood as an occurrence as it is apprehended, perceived or experienced by a person (Dahlberg et al, 2001).

Sampling

The sampling of participants for the study was made among the 40 relatives who participated in the first six support groups. A strategic selection was made with regard to the participants’ age, gender and relation to the patient in order to get as many experiences as possible. The informant was to have attended at least five of the six support group meetings and the aim was to achieve a variation of participants from different groups. Thirteen participants were approached for the purpose of securing an interview, of whom three declined. A total of ten people were interviewed; eight women and two men, seven were spouses and three were daughters. The participants were between the ages of 35 to 85. The sampling reflected the participants in the different groups. A wife and daughter were from the same family. At the time of the interviews, eight of the ten patients had died.
Data collection
Qualitative interviews in the form of open dialogues were chosen as the data collection method. A written request and information about the study were sent by mail and followed up a few days later with a telephone call. When being asked to participate in this study, it was emphasised that the participation was voluntary, with the option to discontinue at any time. At the time of the inquiry, verbal information about the study was given and signed consent was collected. The participants were given the choice as to where the interview should take place. Four participants chose their own home and six chose the palliative care unit. Two participants who were part of the same family chose to be interviewed together. The length of the interviews varied between 30 and 90 minutes.

The interviews started with the following question: How did you experience the participation in the support group programme? The interviewer tried not to take anything for granted, but questioned the relative in a neutral way and followed up with further questions so that the interviewed person recounted more, deepening his or her narrative. The interviewer, who worked as a nurse at the unit, stressed the importance of the informant being as open-minded as possible and emphasised the equal importance of both positive and negative experiences. All interviews were transcribed and analysed by one of the authors (AH). The interviews and analyses were performed in Swedish and translated into English afterwards.

Process of analysis
The analysis was inspired by the phenomenological method as described by Amadeo Giorgi (Giorgi, 1989; Giorgi and Giorgi, 2003). The transcribed text was read simultaneously while the taped interviews were listened to. This was done to acquire an understanding of the relatives’ accounts, for the language used and to acquire an overall sense of the material. The text was re-read and units of meaning were derived which were marked with separating slashes in the text.

The units of meaning were transcribed through a number of steps, which involved concentrating the original text and transforming the participants’ spoken language to a condensed, written language seen from a nursing perspective. The author carefully expressed the nursing meaning of the relatives’ everyday language with the help of free imaginative variations.

The units of meaning were synthesised into a structure for each interview where several key constituents were generated (see Figure 1).

Each synthesis was thereafter re-read several times and put in relation to the others. In the end, all the syntheses were compiled into a general structure with

<table>
<thead>
<tr>
<th>Meeting number</th>
<th>Subject</th>
<th>Speaker</th>
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<tbody>
<tr>
<td>First</td>
<td>Presentation of the nursing unit</td>
<td>Course organiser</td>
</tr>
<tr>
<td></td>
<td>Presentation of participants</td>
<td></td>
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<tr>
<td></td>
<td>Nutritionist nurse</td>
<td></td>
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<tr>
<td></td>
<td>Trial tasting and a few tips</td>
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<tr>
<td>Second</td>
<td>What is palliative care?</td>
<td>Doctor</td>
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<tr>
<td></td>
<td>What does palliative care consist of?</td>
<td></td>
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<tr>
<td></td>
<td>Definition, philosophy, symptoms, supportive care</td>
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<tr>
<td>Third</td>
<td>To live in proximity of a severely ill person</td>
<td>Almoner</td>
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<td></td>
<td>Practical problems (economy, subsidies, home assistance), crisis, crisis management</td>
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<tr>
<td>Fourth</td>
<td>Handling day-to-day life</td>
<td>Physiotherapist and occupational therapist</td>
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<tr>
<td>Fifth</td>
<td>When life is on the edge</td>
<td>Hospital priest</td>
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<td></td>
<td>Sorrow, coping, existential questions</td>
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<tr>
<td>Sixth</td>
<td>Me as a caregiver</td>
<td>Course organiser</td>
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<tr>
<td></td>
<td>Where can I find strength?</td>
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<td></td>
<td>End of programme, conclusion</td>
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six key constituents. An overall essence or underlying meaning in all key constituents was identified and formulated.

In order to remain as open as possible towards the gathered data and to avoid bias during the analysis, the authors attempted to be constantly aware of their own preconceptions and continuously question the results during the process of analysis (Giorgi and Giorgi, 2003). Ethical consent for the study was obtained from the ethical research committee, Karolinska Institute, Stockholm (no. 04-212/1).

Findings
During the process of analysis a general structure appeared featuring six key constituents (see Figure 1). The key constituents were not separate from each other but overlapped partly and were to some extent even dependent on each other. In all key constituents there was a recurring and common meaning – safety – that made up the overall essence of the experience and the importance of support groups for relatives of patients in palliative care.

Confirmation
The participants’ sense of confirmation clearly appeared in the interviews and consisted of various parts. To be invited to participate in a support group was confirming. It gave the participants a sense of importance, that they mattered and were a resource for the patient. They felt seen and confirmed as individuals with their own feelings, thoughts and needs.

‘It was worth a lot; it signalled that I was important and that I was an asset to my sick relative. One felt enormously confirmed.’

The information given in the support group sessions was affirmative as the participants acquired knowledge about normal crisis reactions and common ways to cope. It was confirming to meet others in a similar situation, to recognise feelings and thoughts and to experience that they were not alone in having these thoughts and reactions.

‘It was so good; you could listen to the others and compare yourself with them.’

The participants also testified about validating the patient. They felt that, through attendance and participation in the support groups, they showed the patient that he or she was important to them. Their participation in the support group programme became a statement which signalled that they were available to help when necessary.

‘It was a statement aimed at her; it showed that I cared.’

The participants also spoke of a reverse sense of validation; by participating in the support group they were themselves being validated by the patient. The patient clearly appreciated the relatives’ participation in the support group, confirming that they had done something important and good.

Figure 1. The six key constituents of the support group
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Table 2. Structure of the support group

<table>
<thead>
<tr>
<th>Stage</th>
<th>Duration</th>
<th>Description</th>
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<tbody>
<tr>
<td>Participants arrive (approx 5 minutes)</td>
<td></td>
<td>Course organiser meets and welcomes participants</td>
</tr>
<tr>
<td>Open conversation (approx 20 minutes)</td>
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<td>Course organiser leads the conversation where all participants are given the opportunity to talk about their present home situation</td>
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<tr>
<td>Today’s theme (approx 45 minutes)</td>
<td></td>
<td>Today’s theme is presented and the invited speaker arrives. The speaker is open for questions and adapts his/her material to the needs of the participants</td>
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<tr>
<td>Conclusion (approx 10 minutes)</td>
<td></td>
<td>Time for reflection and thought. How did the participants perceive what the speaker talked about? Is it something that they recognise?</td>
</tr>
<tr>
<td>Course organiser concludes the meeting</td>
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‘You could at once tell by looking at her that she appreciated it and felt that it gave her something, because it gave me something.’

Insight into gravity of the illness

The participation in the support group gave rise to insights that their relative would not survive the illness as the lecturers provided information about the gravity of the illness. Furthermore, by being part of the other participants’ experiences, the relatives gained additional knowledge of the nature of the illness. Most participants considered these insights as positive, helping them to handle the situation. It was, in fact, important to be confronted with the difficulties, which prepared them for what was to come. This feeling of preparedness diminished the fear of what would eventually happen and less energy was spent on worrying about it. In addition, it gave them a sense of control over the situation, which was perceived as important as they felt powerless when having to face their next of kin’s impending death. For some participants, these insights facilitated their acceptance of the present situation, helping them to make good use of the remaining time with the patient.

‘I think it gave me an insight as to where we were headed. I had to face the situation as it was and to accept it, I think.’

‘I felt safe and aware about the fact that he will die. It is of course a terror in itself, but it was good to receive information bit by bit and step by step because then one could start the process.’

Some participants felt that they had difficulties digesting the information that at times felt distant and not related to their own situation. They had difficulties perceiving their relatives as fatally ill, as their illness had not yet progressed to this extent.

‘Right then it felt quite good. It is really good that one talks of these things but it doesn’t really concern us. It lies further ahead.’

Sense of belonging created by similar experiences

The participants enjoyed meeting others in the group since they knew all were there because they had someone near to them who was seriously ill. A sense of belonging was created by sharing a similar life situation and the concomitant experiences, which were not dependent upon age, gender or relationship to the ill individual. The participants experienced a real feeling of community and shared, after some time, many things about themselves. They spoke about how life was when being a next of kin to a terminally ill patient and gave each other advice on how to find solutions to problems encountered in everyday life. The participants talked about having different attitudes towards the illness and how they handled the fact that their relative was going to die. Finding themselves to be in a similar situation was liberating for the participants, freeing them from unnecessary questions and the obligation to explain how they were and how they felt.

‘At the beginning I don’t think I realised what it would mean to me. In any case, it is very nice to be able to sit with people you don’t know and who are in the same situation. Actually one has quite a lot to talk about.’

‘You are here with people who don’t need to ask questions because they know.’

The support group gave the participants an opportunity to compare and identify
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‘For many participants the participation in the support group led to increased conversations with the patient and they felt more empowered to talk about the illness’

themselves with others, which helped them to handle their own situation. It was not perceived as a burden to take part in the other participants’ experiences; instead, it confirmed them in their own sorrow. Several participants said it gave them an opportunity for reflection and they attempted to find the positive aspects of their situation. One informant stated that it was difficult to talk about him/herself in front of the others, but that it was useful to hear the others’ experiences. Several participants found satisfaction in that they were able to provide support to the others in the group.

However, there were also participants who recounted that they did not receive the expected response when giving expression to their own thoughts and reflections. Therefore, they experienced a lesser degree of support than the other group participants.

Participation in the caring system
To be invited into the group created a feeling of participation and the participants obtained a clearer view of the care unit’s organisation, the unit’s various professional staff categories and what assistance was available to them.

‘Mostly this made it very easy to make contact, as I knew who I could talk to.’

Being in the care unit during the group meetings, getting to know the personnel and being allowed to move around in the ward environment created a sense of increased participation. The participants had the feeling of developing a trusting relationship with the nursing staff in the care unit and they felt invited to take part in the care of the patient. It became clear to the participants that they were an important resource for the patient and they cared for the patient together with the nursing staff.

‘It felt as though we were, on the one hand, next of kin and on the other, part of the nursing system.’

Furthermore, several participants expressed that they had a feeling of increased participation in the care of the patient. They learned more about the illness, symptoms and how to best assist the patient in different ways. This knowledge created closeness between the patient and staff since the relatives then felt more secure about how to best help and make the most of the remaining time.

Being able to rest
Rest consisted of being able to take a break from caring during the duration of the meetings. The meetings were a refuge from the otherwise pressured life situation where they identified themselves as givers. The participants said that it was very helpful to be given access to pertinent information and not to have to spend time and energy looking for it. The meetings provided emotional support and were an opportunity to recuperate in a calm and peaceful atmosphere.

The participants saw the support group as a forum solely for them, where they could openly conduct conversations about their thoughts, worries and fears. It was restful to be with others who understood and where they did not have to dissemble their feelings or feel unwanted demands. The participants felt restful just being allowed to be. Furthermore, it was a defensible rest since they had a good reason for being there; they participated in part for their own needs but also in order to better be able to help the patient. It was a moment of relief and a pause in the caring without having to feel guilty of not attending to the patient’s needs.

However, for the participants who had a relative who was alone at home, or who was anxious or restless, the participation in these group meetings could instead create more stress rather than being restful because they felt that they were somehow abandoning the patient.

Several participants expressed feeling joy when going to the support group meetings. It was a joy to spend time at the support group and for some it was the only occasion to leave their home. They appreciated being served and offered something to eat and drink. To summarise, the participation in the support group was a legitimate rest for the participants as they had been invited by nursing staff that cared for the patient.

Strength to constitute a support for the patient
Participation in the support group gave the participants strength to face the patient and their need for practical nursing care. They were fortified by their knowledge,
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‘To be seen, confirmed and to understand that they were important, and were counted upon as a resource, created a sense of safety among the participants’

which facilitated the caring of the patient. The participants received practical advice and information, and therefore felt more secure in their caring role. It was strengthening to feel that their participation in the support group directly or indirectly benefited the patient and satisfying to manage the care more professionally than before.

For many participants, attendance at the support group led to increased conversations with the patient and they felt more empowered to talk about the illness and the fact that the illness would lead to death. These conversations gave them a chance to speak about events that had occurred earlier in life, straightening out any unresolved issues between the informant and the patient. Some of the participants gained strength to dare to talk about the patient’s wishes regarding their funeral. This, in retrospect, gave them satisfaction, as they were able to arrange the funeral according to the patient’s wishes. The participants felt that they were fortified and encouraged to meet the patient in their thoughts about death. Some participants were not able to bring themselves to talk with their relative; they could, however, feel strength in being prepared to meet the patient in a conversation if they wished.

‘I think it turned out quite well for me. That I had it in my body and soul and was able to wait for what might emerge from him. I was prepared, I was one step ahead.’

‘I have thought about it a great deal. I know that I was strengthened in coping in a whole new way. I was incredibly prepared and this made me strong to cope, to cope for his sake and for my own, such as I hadn’t been able to do otherwise.’

There were also participants who expressed that it was difficult to be encouraged to talk about death with the patient. These participants did not want to cause their relative to be sad, worried or upset. In other words, they wanted to protect the patient from such thoughts.

Essence: a sense of safety

The six key constituents resulted in the participants becoming secure in their relation to the patient, the illness, the nursing staff and the care unit. This sense of safety generated a feeling of being able to care for and face their sick relatives in a better and more assured manner than before. They felt more capable of handling the situation and several participants felt safe enough, despite severe illness, to care for their relatives in the home setting until the moment of death. There were also participants who realised that they either did not want, were not able, or were too tired, to care for their relatives at home. However, these participants felt sufficiently safe to convey this to their family members and the nursing staff. According to the participants, this sense of safety benefited themselves as well as the sick relative. Several participants claimed they felt that their relative had had a rewarding end of life, partly due to the sense of safety gained by the participants and its expression in their handling of the situation.

‘He actually had a fantastic time at the end, mainly because we felt so safe.’

‘All this created a safety which made me feel more secure in relation to him.’

‘It turned out that we were calm. We could talk to each other and we received very much from the group.’

Discussion

The results of the study showed that relatives of terminally ill patients benefited from the support group during the late palliative phase, and that the participation in some way provided relief in their day-to-day lives. This participation provided an opportunity for a moment of rest and an exchange of experiences with others in a similar situation. Confirmation and the feeling of participation were an important part of the relatives’ experiences and they experienced an increased insight and strength in caring and being with the patient.

The results of the study are in concordance with the relatively few other existing studies about support groups for relatives during the late palliative phase (Harding et al, 2002; Witskowski and Carlsson, 2004). Witskowski and Carlsson (2004) found that the support group provided a preparation for what would eventually happen. The present study also showed that the participants had become prepared through an increased insight and understanding, which gave them a sense of safety.
‘This study highlighted that it was important for the participants to provide support for each other by contributing and sharing their experiences’

in relation to the illness. Participation in the support group may have given the relatives an advantage over the illness, even if the insights at times were hard to bear.

To be seen, confirmed and to understand that they were important and were counted upon as a resource created a sense of safety among the participants. A parallel to the work of Andershed (1998) can be drawn here, where the relatives’ ‘involvement in the light’ meant being seen and confirmed by the nursing staff and where the participation meant building a cooperation and a ‘partnership’ between relatives, nursing staff and the patient. One conclusion can probably be drawn: the support group contributed to the increase in the relatives’ sense of ‘involvement in the light’.

The support groups were experienced as a restful refuge, to just sit and receive. It provided an opportunity for reflection in peace and quiet. Harding et al (2002), as well as Witskowski and Carlsson (2004), confirm the present study’s results as they report relatives who expressed that participation in a support group gave them a break from caring, an opportunity to leave the home environment and to have a private moment to ‘catch their breath’.

Relatives in this study experienced safety in meeting others in the same situation. It confirmed many of the relatives’ feelings and thoughts. The emergence of a sense of belonging was expected to manifest itself in these support groups, but it is also important to identify which factors caused this feeling of belonging and in what way it could be described. In the present study the sense of belonging clearly sprang from the participants finding themselves in a similar situation rather than from other common denominators such as, for instance, gender and age. The participants appreciated that the groups were mixed in this aspect and even expressed that it enriched the group and contributed to the exchange of more experiences. This is somewhat confirmed in the study of Witskowski et al (2004), where all men and most women said that they were satisfied with mixed groups. However, some women did prefer a more homogenous group, for example only women. The present study shows, just like Witskowskis et al (2004) and Hardings et al (2002), the importance of meeting others in order to be able to identify with them, and to confirm feelings and exchange experiences. As a result, a feeling of not being alone in this situation arises. The crucial part of this process seemed to be the growth of a silent and mutual comprehension where no explanations were necessary between group participants. This study highlighted that it was important for the participants to provide support for each other by contributing and sharing their experiences, which is concurred by Harding et al (2002) and Witskowski and Carlsson (2004). The participants felt they acquired strength to handle their own situation but also strength to face the patient in their thoughts and broodings about death and other existential matters.

It is difficult to separate this study’s results from the other care interventions given. Therefore, the support group programme should not be regarded as a separate intervention but as a complement to existing nursing care. The sense of belonging can be discerned as a clear effect of the support group programme. In addition, through the sharing of common experiences and the exchange of information, a foundation has been built upon which the relatives have achieved and benefited from a certain amount of confirmation and insight. Rest is also a clear benefit resulting from the support group programme. Further, the personal strength described may be derived from the support groups, but may also have originated from the daily contacts with nursing personnel in the day-to-day care. The feeling of participation probably springs from the support groups, together with the impact of palliative care activities. The existence of the groups most likely have enriched the sense of confirmation gained since their creation have signalled that the relatives do matter in the palliative care system.

**Limitations of the study**

The participants were aware that the interviewer worked as a nurse at the care unit in which the patient was cared for. Therefore, the participants may have given predominantly positive answers to the interviewer’s questions, avoiding voicing critical comments due to a sense of gratitude. This could have influenced the results. However, the participants received clear information that their experiences

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of the support group programme would be the basis for a possible revision and improvement of the programme. It was also clearly explained that the interviewer would pay equal attention to both positive and negative experiences arising from the programme. In addition, it is estimated that the authors have managed to keep their preconceptions at bay during the process. An important limitation inherent in the study is the issue of self-selection. The participants who chose to take part in the study may have had a positive attitude towards the programme. In any case, there were several participants who initially expressed doubts about participating in this study and who, just the same, found that they had benefited from their participation.

Conclusions

Based upon the results that have emerged about relatives in palliative care, the authors consider this study to have clinical relevance. The study's results show that these kinds of nursing interventions, initiated and carried out by nurses, may significantly influence the relatives' possibilities of handling their situation when caring for a terminally ill person. The study can inspire and help other nurses to carry out similar interventions with the explicit purpose to support relatives in palliative care, as these constitute an exposed and vulnerable group with great need of support. Furthermore, the study shows that it is possible within nursing to carry out supporting interventions with small resources.