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*“A rewarding conclusion of the
relationship”:*
Staff members’ perspectives on providing
bereavement-follow-up

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Abstract

Goals of work: Staff members in palliative home care play an important role in supporting bereaved family members. The aim of this study was to explore staff members' perspectives on providing such support. *Material and methods:* Staff members in six units responded (n=120; response rate 58%) to a postal questionnaire with Likert-type and open-ended questions. The responses were analyzed using statistics and manifest content analysis. *Main results:* None of the respondents stated that bereavement follow-up was "most often difficult", 23%, "most often rather difficult", 52.5% "most often rather easy" and 12.5% "most often easy". Apart from a tendency for age to be linked to perceived difficulty, there were no apparent patterns. Bereavement follow-up was a positive opportunity to support the family member's coping with their bereavement and to get feedback on the palliative care provided. Critical aspects concerned the question of whose needs actually were being met at bereavement follow-up, i.e. the staff members' needs for getting feedback on the care provided vs. the risk of burdening the family members' by reminding them of the deceased's dying trajectory. Aspects that negatively influenced the staff members' experiences were complex and related e.g. to the family member's dissatisfaction with the care provided, to the staff member's perceived lack of competence and to the staff member's relationship to the family member. *Conclusions:* Bereavement follow-up was perceived as a rewarding conclusion to the relationship with the family member. The findings suggest that meaning-based coping might be an appropriate framework when understanding staff members' experiences with providing bereavement follow-up.

Key words: Bereavement follow-up, staff member, conclude, burden

Introduction

In palliative care there is a long tradition of considering family members as a unit of care [11], and bereavement support is included in WHO's definition of palliative care [48].

Consequently, many services working with dying patients offer such support - 74-98% according to some figures [16, 31, 32, 41, 50]. The most common type of bereavement support is when someone from the team (most often a nurse) visits or phones the bereaved person, usually once, at home or meets the family member in the ward some weeks after the patient's death [6, 13, 16, 26, 31, 32, 40, 50]. For example, in the UK, 96% of the hospices offer bereaved people individual meetings and 90% offer some form of telephone support [13] and in Australian palliative care services the numbers are 84% and 86%, respectively [31]. There seems to be no established term for this kind of support and different labels have been used for similar types of bereavement support: "one-off counseling" [40], "a supportive telephone call after the death of a significant other" [26], and "bereavement follow-up" [6]. In this study we have chosen to use the term "bereavement follow-up" for this support [6].

The experience of dying, from a socio-historical perspective, has gradually become more private at the same time as its recognition has become more publicly controlled and defined [27], and this also seems to have consequences for the grieving family member. Some authors have suggested that social changes within society have reduced the availability of social support as well as the willingness of people to confide in close family and friends [13].

Although we do not know at present whether routinely offering bereavement support to all family members actually facilitates adaptation to bereavement [10, 25, 45], bereavement follow-up is perceived as important by a substantial number of the bereaved. In one of our previous studies, 46% (n=248; response rate 66%) of the family members of a deceased patient expressed a need for bereavement follow-up, and 61 % of the respondents

avored an individual visit, preferably in their own home, with the staff member who had had the most contact with the patient and the family. The follow-up procedure made the family member experience a feeling of being recognized as a person with his/her own needs, and it was valuable to talk to the staff member about the family member's feelings of guilt [35]. In addition, in Kaunonen et al.'s study 72% of the bereaved family members that had received a supportive telephone call four weeks after the death reported that the nurse's phone call had an impact on how they perceived the death [26].

It is increasingly common that dying patients are cared for at home with help from palliative care teams. Studies have shown that such care at home may have positive implications for the family caregivers, e.g. through a sense of meaningfulness and the opportunity given to them to express their love through care [19] [36]. However, it may also be burdensome to the family caregivers, with consequences for their health and quality of life, through substantial degrees of anxiety, depression, exhaustion, poorer physical health, existential suffering and negative role changes during the patient's deterioration [28, 47][38] [37], Wennman-Larsen et al. interviewed family caregivers of cancer patients enrolled in advanced home care [47]. The family caregivers described themselves as the persons bearing the primary responsibility and providing care for their dying relatives. They were found to have many concerns about their own situation, especially in regard to issues temporarily after the death of the patient, but seemed to have few expected sources of support related to these concerns. Other studies have also illuminated that family members of patients enrolled in palliative home care may feel abandoned and alone with the burdensome responsibility of taking care of the patient despite their lack of competence [37]. After the palliative home care period, i.e. when the patient had died, the family member might struggle with intense feelings of loss, loneliness, anger, guilt and doubts about whether they had done enough for the patient [38].

Staff members have an important role in supporting family members during their bereavement - one of the most highly stressful experiences [23]. According to our clinical experience, staff members sometimes express that they perceive difficulties when carrying out bereavement follow-up. There are, however, only limited reports concerning staff members' experiences in relation to providing bereavement follow-up. Jackson conducted an interview study of critical care nurses' perceptions of bereavement follow-up services. Nurses, who performed the follow-up service, perceived this to be an appropriate function within their role and had positive attitudes toward it. Themes that emerged in the qualitative analysis were the benefits to relatives and staff, difficulties in making the calls, developing a rapport with the relatives of patients who had only been in the unit a short time prior to their death and relatives who might not have appreciated a call [24]. Kaunonen et al. studied the oncology ward nurses' perspective concerning a supportive telephone call after the death of a significant other. During the call, nurses were able to evaluate the family's coping. They also got feedback concerning the nursing care delivered. The call served as a "finishing analysis" of the family nursing process.

Although bereavement follow-up is routinely performed in many palliative care services and a lot of clinical time is allocated to this, to our knowledge there has not been any study of staff members' experiences of providing such support within the palliative home care setting. Therefore, the aim of the study was to explore staff members' perspectives on providing bereavement follow-up in palliative home care: i) to quantify the perceived importance of bereavement follow-up, allocation of resources, time spent and also the staff members' assessments (in terms of difficulty or ease) of providing bereavement follow-up; ii) to qualitatively describe the staff members' perception of providing bereavement follow-up.

Patients and methods

Study population

This study has used a mixed methodology, with a cross-sectional design with sampling in six different units providing palliative home care in the southeast of Sweden. These units were chosen to get a rich variation concerning staff members' perceptions of providing bereavement follow-up in palliative care. In Sweden as well as in other countries palliative care and bereavement support is also considered to be part of primary care, not only a matter for specialized palliative care services [3, 29]. Therefore, the study context was three advanced palliative home care teams (APHC) and three primary care services in Sweden.

There were some differences in the units as to which occupation/occupations that actually performed bereavement follow-up, and only members of the professions that were used to carrying out bereavement follow-up at the unit were included. All staff members (of the professions that used to carry out bereavement follow-up at the unit) were identified through existing databases at the units and were mailed an invitation letter and an uncoded questionnaire. A reminder was sent after two to four weeks. During the study period 208 staff members were available according to the inclusion criteria and of these 120 responded to the questionnaire (response rate 58%). The characteristics of the respondents are presented in Table 1. Since the questionnaire was submitted anonymously, a formal analysis of the drop-out-rate was not possible, but there was no major difference between the respondents and non-respondents in gender ratio (study population 97% females vs. respondents 96%), in median age (both groups 49 years) and in the distribution of different professions (nurses 64% vs. 67%; nursing assistants 25% vs. 20%; doctors 7% vs. 5%; others 4% vs. 8%).

Data collection

A postal questionnaire was constructed with both a quantitative and a qualitative part.

Although open-ended questionnaires are a data collection method that may result in less richness in the descriptions compared to interviews, it may lead to greater generalizability because of the larger possible numbers of informants. In addition, postal questionnaires may be better than interviews in enabling respondents to express negative experiences, e.g. dissatisfaction [2]. The content of the questionnaire was developed according to the aim of the study, previous research and the research group's clinical experience.

The minor quantitative part (placed first in the questionnaire) consisted of questions concerning the background data of the staff member (such as age, gender, profession, number of years working in palliative care, number of times having performed bereavement follow-up over the last year), approximate time spent for a typical bereavement follow-up, their opinion regarding two statements: i) "Bereavement follow-up is an important part of palliative care"; ii) "My unit allocates enough resources to bereavement follow-up" (4-grade Likert type; from "Disagree" to "Fully agree") and assessment of performing bereavement follow-up (4-grade Likert type; from "Most often difficult" to "Most often easy").

The qualitative part (the main focus of the questionnaire) consisted of open-ended questions where the staff members were asked to describe in their own words, their perception of performing bereavement follow-up, such as: "According to your experience, are there any difficulties in performing bereavement follow-up? If so, what?", "How do you usually manage or cope with such difficulties? "What if anything can be of help?" "In your experience, are there any positive aspects to performing bereavement follow-up? If so, what are they?" In addition, the staff member was also asked to give reasons, ("Why do you think so?"), both to his/her opinion about the two statements concerning the importance of bereavement follow-up and allocation of resources (see above) and his/her assessment of

performing bereavement follow-up. Each open-ended question was followed by four or five blank lines. The respondents were encouraged in the instructions to use the (blank) backs of the questionnaire (A4 format) if they needed more space. The questionnaire ended with “Is there anything else you would like to add regarding bereavement follow-up?”.

Content validity and feasibility were checked by clinic staff experienced in palliative care (n=2) and palliative care researchers (n=2), who were not otherwise involved in the study. This showed that the questionnaire was feasible and only minor changes were made mainly due to some ambiguous phrasing that was subsequently removed. In addition, a pilot study was performed, which showed that the questionnaire worked well, i.e. rich responses to the open-ended questions, an acceptable response rate and distribution of the responses over the Likert scales. Therefore, no further changes were made. Data was collected between the winter of 2005 and the spring of 2006.

Analysis

Quantitative data were summarized in box plots, and evaluated in χ^2 -tests. The responses to the open-ended questions were analyzed using manifest qualitative content analysis with no preconceived codes [18]. The applicability of qualitative content analysis as a method for the analysis of open-ended questions in questionnaires has been previously described [21].

The analysis of the qualitative data was performed using the following steps: Firstly, all the responses were read through to obtain a sense of the whole and to develop themes. Secondly, the responses were systematically re-read, line by line, to identify significant text segments, i.e. “meaning units” and to develop matching codes; preliminary categories. The actual words written by staff members were used to the greatest possible extent. Thirdly, the statements in each preliminary category were scrutinized and compared to find their central component. Fourthly, the final categories were compared to avoid obvious overlapping, and content descriptions and relations to other categories were developed. The

respondents' answers to all the open-ended questions were seen as the unit of analysis, and the final categories emerged in the analysis of the answers which all the respondents gave to all the questions.

Coding and the development of categories were mainly done by the first author, while the co-authors concentrated on reviewing the findings. The categories were discussed until agreement was reached. Involving several researchers is a way of reducing the risk of investigator bias, by researchers supplementing and contesting each other's readings, corresponding to reflexivity [30]. To further strengthen the validity, peer debriefings were conducted where the results were presented and discussed in research seminars involving clinically-experienced staff members and social workers, as well as senior researchers.

Results

Quantitative results

The analysis of the quantitative data showed that 96% of the staff members responding partly or fully agreed with the statement that bereavement follow-up is an important part of palliative care, and 90% partly or fully agreed with the statement that their unit allocates enough resources to bereavement follow-up. Twenty three per cent had experienced that bereavement follow-up was "most often rather difficult", 52.5 per cent "most often rather easy" and 12.5 per cent "most often easy". Exploratory analysis revealed no clear differences between different settings or different occupations (Table 2). Furthermore, experience (i.e. number of bereavement follow-ups or work experience in palliative care) had little influence on the perceived difficulty performing bereavement follow-up (Figures 1a-b). However, there was a tendency for the perceived difficulty to diminish with age of the respondent (Figure 1c). More details of the quantitative results are shown in Table 3.

Fig. 1 a–c: Staff members' assessment of performing bereavement follow-up versus workload, experiences, and age

Qualitative results

Ten categories emerged in the analysis of the responses to all the open-ended questions. Some respondents wrote extensive descriptions of their experience in providing bereavement follow-up in palliative home care, and others wrote only a few words or nothing. The categories concerned two areas: i) Perceptions of performing bereavement follow-up; ii) Aspects influencing the perception of performing bereavement follow-up (six categories). An overview of the areas and the categories is presented in Table 4.

i) Perceptions of performing bereavement follow-up

1) A rewarding conclusion of the relationship

Many of the respondents mentioned the importance for both the family member and the staff member to conclude their relationship. Some of the staff members had thought about the family members many times after the patient's death, wondered how they were doing and also felt sadness and grief themselves for the patient that they had cared for and who was now dead.

"... sometimes, after a long period of caring for a sick person, you need to grieve too.

Sometimes the patient had come to a difficult end, and the family too" (54-year-old female nurse with 20 years of work experience in palliative care)

"It is important to move on both for family members and staff members. Bereavement follow-up is a way of putting it [the palliative care period] behind us" (Female nursing assistant with 23 years of work experience in palliative care)

To meet the family member again after the patient's death was described as rewarding, although it could sometimes also be distressing. It was valuable for the staff members to bring

their caring role to an end by getting this opportunity to see how the individual family member was coping, but also to reflect on, and be fascinated by people's ability to adjust to difficult life situations and move on in life despite the death of a loved one.

"You take some of the great sorrow of the family member with you. Sometimes I cry in the car... These meetings give you so much, but also they drain a lot of your inner strength. It is difficult just to go on with your usual nursing tasks afterwards." (38-year-old female nurse with twelve years of work experience in palliative care)

"One gets the full picture of the deceased and his/her family [at the bereavement follow-up] Most often it turns out to a dignified conclusion of the care that we have provided. It feels good actually" (50-year-old nursing assistant with ten years of work experience in palliative care)

[Do you think there is something positive in performing bereavement follow-up?] *"That so many people are so resourceful to cope with difficulties, and most of them manage well"* (55-year-old female nurse with ten years of work experience in palliative care)

Some doctors, physiotherapists and occupational therapists stressed that they would appreciate to have this opportunity of meeting the family members after the death of the patient more often. The respondents' also expressed that the satisfaction of concluding the relationship did not only concern the individual, who actually met the family member, as it was also mentioned as a positive experience when the team made a closure together at a meeting when one of the staff members shared aspects that had come up at the bereavement follow-up.

2) To support family members' coping with bereavement

The respondents expressed a positive experience with bereavement follow-up due to the opportunity to support the family members coping with bereavement, e.g. responding to family members' questions that frequently came up after the patient's death "*when the sorrow and fear have subsided and they start to contemplate*". In addition, staff members could assess how the family members were coping with bereavement and when concerns arose they tried to give him/her extra support or refer them for further consultation.

"[The bereavement follow-up] gives them [the family members] an opportunity to talk over the last difficult time with someone. Often they do not have anyone else to share this with, because it's hard for others to understand." (40-year-old female nurse with three years of work experience in palliative care)

3) To get feedback on the palliative care provided

It was satisfying for the respondents to get feedback at the bereavement follow-up from the family members about how they had experienced the palliative care period - what had worked well and what could have been done in another better way. When the feedback was positive, "*it felt good inside*". By trying to improve the quality of care, staff members found it easier to cope with both negative feedback and aspects they themselves were not satisfied with, e.g. lack of symptom control.

[Do you think there is something positive about performing bereavement follow-up?] To meet the family members after the patient has died, [to see] how their life has moved on, despite what has happened. The time when the loved one was ill can now be talked about, what it was like. Feedback. What could have been done differently? ... A closure. (56-year-old female nurse with ten years of work experience in palliative care)

“[It is positive] when family members confirm that our efforts were helpful. It is important for us to know what worked and what was less helpful. So that we can be as efficient as possible.” (60-year-old nurse with 15 years of work experience in palliative care)

4) Whose needs are being met?

There were, however, also concerns among the respondents about how ideal the situation is for family members at a bereavement follow-up to provide feedback about care quality directly to the staff members involved in the care itself, namely, the risk of family members not mentioning any negative aspects.

“I have thought about swapping bereavement follow-ups with a colleague, to avoid me having that connection with the family and the patient, that makes it difficult. It would make it easier for the family member to honestly evaluate the care and me as a nurse” (48-year-old female nurse with 19 years of work experience in palliative care)

According to the staff members, most family members were coping well with their loss and not all family members were in need of talking to a staff member during bereavement, and therefore a few staff members thought it was a waste of resources to offer everyone bereavement follow-up. In addition, bereavement follow-up could actually have negative consequences and burden the family member, according to the respondents' experiences.

“Sometimes it feels as if you're reopening a sore that has healed . As a APHC staff member you strongly remind them of the sick person that has just died” (53-year-old female nurse with 27 years of work experience in palliative care)

Some of the respondents raised questions about whose needs were actually being met in bereavement follow-up. Although, the bereavement follow-up could be a support for the family member and also provide important feedback for improving the services, the contact met some needs of the staff members such as providing important feedback concerning themselves as staff members and valuable knowledge for the staff member on how human beings can cope with difficult life situations, such as bereavement. Several respondents stressed the importance of the family members' willingness to talk and that staff members were sensitive to the family members' wishes and were not intruding when contacting the bereaved. Some described telephone calls as less intrusive than home visits, and therefore more suitable for some family members; others felt that home visits were better.

ii) Aspects influencing the perception of performing bereavement follow-up

1) The family members' coping and acceptance

Most family members were coping well, and often expressed a positive attitude when the staff member contacted them, according to the respondents. However, some family members expressed deep distress, despair, powerlessness or dissatisfaction with the care. According to the respondents, they could also be aggressive, be caught up in bitterness or not be able to accept the loss of the deceased. Such circumstances made it difficult to perform the bereavement follow-up and the staff members felt powerless, but sometimes they also felt empathy and compassion.

"It is always hard to face the strong pain in grief. Sometimes it can go on for months and years". (Social worker)

2) Their own competence, experience and coping

Long experience in palliative care and one's own skills in communication were mentioned as facilitating aspects. Such aspects included having confidence in how to talk about sensitive matters, how to listen and acknowledge the family member's feelings and explore what is

experienced as helpful to the bereaved person when managing difficulties in life. In addition, knowing how to deal with dissatisfaction, sorrow, anger and silence during the talk were also mentioned.

It was difficult when feeling uncertain regarding how to assess certain situations, e.g. what is normal with regard to coping with bereavement, and not feeling competent enough concerning medical issues as well as handling existential matters, such as the “why?” questions. If the staff member thought that there had been problems in relation to care quality, such as lack of symptom control, staff members lacking in knowledge, a delayed diagnosis, all of these could negatively influence the staff member’s perception of providing bereavement follow-up. In addition, the staff members’ coping with their own grief, that the patient’s death reminded them of, had also an impact.

“When you can feel the loss in yourself, and you know how it feels, then it is difficult.” (50-year-old nursing assistant with eleven years of work experience in palliative care)

3) The relationship to the family member

It was helpful when the family members were open-minded and easy to have a rapport with and if the staff member knew the family from previous contacts (first quotation below). In contrast, it was often experienced as difficult for the staff member if the family member was young, seemed lonely, was quiet, distant or reserved in the contact time, had been through several losses of this kind or was too attached and dependent on the contacts with the staff member (second quotation below).

“It is easy if you have had a relationship with the deceased and his or her family during the care period ... It [bereavement follow-up] is about so much more than what’s written in the medical records, and the actual physical death”. (43-year-old female nurse with 15 years of work experience in palliative care)

”[It is difficult] when family members are reserved when we talk to them. Sometimes they have been through losses of this kind that they connect with their present situation. It’s difficult to face feelings of despair and powerlessness” (55-year-old female nurse with ten years of work experience in palliative care)

4) Time, peace and setting priorities in the units

Some staff members expressed that providing bereavement follow-up was easy, because it was an unquestionable part of their work that all the family members of deceased patients should be offered bereavement follow-up. Other respondents felt that, due to the heavy workload, they had to make an active choice and often bereavement follow-up was not given priority. It was not only the actual meeting that took time; it was the preparation beforehand (e.g. reading the medical records), the transportation and the documentation afterwards. The respondents stressed the need for peace and quiet in relation to bereavement follow-up.

“It is difficult to find the time to call [the family member], it’s always given low priority. I have always a bad conscience about it” (38-year-old female nurse with three years of work experience of palliative care)

5) Support for the staff members

It was perceived as supportive to have an open atmosphere in the team. This gave people confidence and made it easy to discuss things with other team members (within and between professions), to refer to or ask for help, such as two staff members going to a bereavement follow-up when there were dissatisfied family members. In contrast, it was difficult feeling alone when having to provide bereavement follow-up. The needs for supervision and training, especially in communication, were mentioned.

"I would like to have more information and support with bereavement follow-up. We can apply for courses in pain management, but there is very little available to do with family members. (30-year-old female nurse with three years of work experience in palliative care)

6) Clarity in aim, format and content

There was extensive experience of an unclear aim, format and content with bereavement follow-up, and this made staff members feel uncertain and lack confidence when performing bereavement follow-up. For example, was the intention to support family members or to assess care quality? Staff members described difficulties in communicating the aim of bereavement follow-up to family members, which resulted in misunderstandings and family members believing that staff member were calling for their own sake, as if the staff member, was a grieving family member. The respondents also expressed a lack of guidance concerning the best time to contact family members, who should be referred for continued support and where to document sensitive things that were said during the bereavement follow-up when there was no medical record for family members.

"We need a more evaluated and structured way of performing bereavement follow-up. It shouldn't be a conversation as if I was a family member" (Female nurse with ten years of work experience in palliative care)

Discussion

How can bereavement follow-up be rewarding for staff members?

Seeing patients improve has been cited by health care workers as one of the most rewarding aspects of their jobs [8], and the absence of this makes working with terminally ill patients particularly difficult. In fact, caring for dying patients has been linked to stress, burnout and

professional grief [33] [42]. Caring for dying people or when coming in contact with loved ones of the deceased may actually have such a strong emotional and existential impact that it might force health care professionals to examine their own anxieties and concerns about death [1, 5].

Despite the fact that a family member may be such a reminder of stress, grief and death, in the present study 78% of the responding staff members fully agreed with that statement that they thought bereavement follow-up is an important part of palliative care. The bereavement follow-up was an opportunity to both support and evaluate the family members' coping, and this is supported by others [26]. In addition, the positive experience was not only in relation to supporting the bereaved. Instead, some of the staff members perceived it as valuable, for their own sake, to meet the family member again after the patient's death and conclude the relationship with the bereaved. This is supported by Kaunonen and co-workers' study where oncology nurses described the fact that a supportive telephone call after the death of a significant other served as a "finishing analysis" of the family nursing process.[26]. So how can it be valuable for staff members in palliative care to conclude the relationship with the bereaved?

During the last decade, meaning has received increased attention in relation to palliative care, stress and bereavement as an important coping strategy [7, 9, 15, 17, 20, 36, 49]. It appears that health practitioners cope more effectively with death-related situations when they find ways to understand and consolidate their experiences into broader meaning structures [22]. For example, Redinbaugh et al. found that 36% of hospitals doctors coped with the loss of a patient by trying to "see the death in a different light to make it seem more positive" [43]. Meaning, a sense of purpose or comfort can be derived in different ways, for example from recognizing that one's work makes a difference in patients' lives [5]. There are actually research groups that have drawn on interventions to enhance staff members' sense of purpose and meaning as a way of addressing the stressors and burdens of oncology care [15].

In this study, staff members in palliative home care described that having personal contact with the family member again at the bereavement follow-up often made the staff members feel that they had done something good for the family. It was positive to e.g. see how the family member was coping with the loss and get feedback about the palliative care that had been provided. Thus the staff members could recognize that their work had made a difference in the family member's and/or the patient's life, i.e. a feeling of meaningfulness. An interesting note was that staff members expressed that a satisfactory conclusion could also be achieved when another staff member in the team had carried out the follow-up. One can speculate, whether it could be that bereavement follow-up is an important opportunity for staff members to perceive meaningfulness to gain strength to continue to cope with stress and burdens that are linked with the work involving death and dying? It is noteworthy that the respondents in this study had a median of eight years of work experience in palliative care, which means that many of them had a long experience of coping with issues related to work with dying patients. It would be interesting, in future research, to address questions concerning the possible long-term effects of bereavement follow-up as a facilitator of meaning-based coping in staff members coping with stress related to working with death and dying.

How to provide support for staff members performing bereavement follow-up?

Although 65% of the staff members responding in this study perceived performing bereavement follow-up as most often quite easy or easy, 23% perceived it as most often quite difficult, and sometimes the follow-up aroused feelings of grief and loss arising from the patient's death or from the meeting with the grieving family member. Although some respondents mentioned work experience in palliative care as helpful, the quantitative analysis showed that such experience had little influence on the perceived difficulty performing

bereavement follow-up. The aspects that had made it difficult were complex and related to the family member (e.g. dissatisfaction with the care provided), to the staff member (e.g. perceived lack of competence), to the staff member's relationship to the family member (e.g. not having met the person during the palliative care period), as well as to the organization (e.g. unclear content or low priority of bereavement follow-up as implicitly or explicitly formulated within the services). The current findings, concerning staff members' own grief and the importance of continuity, a clear rational and adequate supervision or training, are not unexpected as they corroborate previous reports [14, 31, 34, 44].

The staff members in this study also mentioned lack of knowledge in medical as well as existential issues as areas that made it particularly difficult for them to perform bereavement follow-up. There seems to be a need for palliative care services to ensure that there is medical knowledge available to consult if needed for the staff member performing bereavement follow-up, and also to allocate resources and time to supervise and educate staff members in existential issues. Previous research has indicated such a lack of competence among staff members in existential issues, e.g. how to handle "why?" questions raised by family members of dying patients [39, 46]. In addition, there seems to be both a need among bereaved to talk with staff members about existential issues [35], and a relationship between stress among health care staff caring for dying patients and encounters with such issues [5, 12]. Moreover, resilience and well-being in palliative care staff seem to be influenced by their awareness of their own spirituality and existential needs, and such an awareness also helps the nurses to address the needs of their patients and their families [1].

The need expressed for concluding the relationship to the family member, mentioned above, was frequent among the respondents and also expressed strongly. It seems important to take this finding into account for services when planning staff support. The respondents in the present study expressed that it was a positive experience when the team met to have a closure together, in relation to a patient's death, with one of the staff members

sharing aspects that had come up at the bereavement follow-up. It seems that memorial services and other inclusive forms of team-designed rituals recognizing losses and patients who have died and their family members in the workplace might have implications for how the stresses of professionals attending to the needs of the dying and the bereaved might be ameliorated [22] [34]. Could making a closure by reflections in the team, of patients' death and their family members be such a ritual recognition of loss in the workplace with potential benefits in secularized countries like Sweden?

So who should be offered bereavement follow-up?

Although bereavement follow-up provides a meaningful opportunity for staff members to conclude a relationship, it also might be potentially harmful. The respondents described concerns about whose needs were being met when performing bereavement follow-up. The respondents also expressed the possibility of bereavement follow-up to all bereaved being a waste of money, and there is support for this since the majority of bereaved persons manage to overcome their grief over the course of time without any interventions [4, 45].

It seems urgent that services have a clear aim for bereavement follow-up and also a formal audit and evaluation of the care quality and effectiveness, so the bereavement follow-up does not turn into one of the few ways of getting feedback for the staff member about the work they have carried out.

Conclusion

Before ending, some methodological considerations will be made. The reader should be aware that the response rate of 56% might have an impact on the transferability of the results. In addition, the present study had a cross-sectional design, and therefore leading to potential recall bias. Future studies should preferably have a longitudinal design and contact should be made with staff members shortly after a bereavement follow-up.

In conclusion, this study of staff members' experience of carrying out bereavement follow-up in palliative home care has shown that 65 per cent perceived it as most often rather easy or easy, but 23 per cent rated it most often rather difficult. Bereavement follow-up was perceived as a rewarding conclusion of the relationship with the family member. It was positive to have an opportunity to support his/her coping with the loss and to get feedback on the palliative care provided. Some critical aspects were elucidated concerning whose needs were actually met at the bereavement follow-up. The findings suggest that meaning-based coping might be an appropriate framework when understanding staff members' experiences of providing bereavement follow-up.

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Table 1
Characteristics of the staff members responding (n=120)

	N (%)	Median (range)	No response* N (%)
Female/ Male	115/ 3 (96/2)		2 (2)
Age		49 (22-65)	14 (12)
Staff member's profession: nurse/nursing assistant/ doctor/ physiotherapist/ occupational therapist/ social worker	80/ 23/ 6/ 3/ 3/ 2 (67/ 19/ 5/ 2/ 2/ 2)		3 (2)
Work place: Specialized palliative home care/ Non- specialized palliative care	95/ 25 (79/ 21)		-
Median years of experience in palliative care		8 (0.1-31)	5 (4)
Median number of bereavement follow-ups performed over the last year		2 (0-60)	12 (10)

*Some respondents had not answered all questions

Table 2

The distribution of responses to the question concerning the staff members' assessments of performing bereavement follow-up.

	Assessment of performing bereavement follow-up*			X ² (p-value)
	Most often rather difficult (n)	Most often rather easy (n)	Most often easy (n)	
Setting				
Staff in advanced palliative home care (n)	23	51	10	2.60
Staff in primary care (n)	5	13	6	(>0.5)
Profession**				
Nurse (n)	18	40	6	0.0090
Nursing assistant (n)	6	14	2	(>0.5)

*One assessment ("Most often difficult") was excluded (n=0)

*Professions rare in study were excluded

Table 3

The responding staff members' (n=120) stated perceptions of providing bereavement follow-up in relation to: importance in palliative care, allocation of resources, time used and their own assessment of performing such support

	N (%)	Median (range)	No response* N (%)
"Bereavement follow-up is an important part of palliative care" Disagree/ Partly agree/ Fully agree	0/ 21/ 94 (0/ 18/ 78)		5 (4)
"My unit allocates enough resources to bereavement follow-up" Disagree/ Partly agree/ Fully agree	3/ 45/ 63 (2/ 38/ 52)		9 (8)
Median approximate time used performing a bereavement follow-up: The talk Other things in relation to the bereavement follow-up such as planning, transportation, documentation		1 h (8 min when telephone calls – 2 h when home visits) 1 h (5 min-3 h)	19 (16) 25 (21)
Assessment of performing bereavement follow-up: Most often difficult/ Most often rather difficult/ Most often rather easy/ Most often easy	0/ 28/ 64/ 16 (0/ 23/ 53/ 13)		12 (10)

*Some respondents had not answered all questions

Table 4

Overview of the qualitative categories that emerged in the analysis of the staff responses to
the open-ended questions

i) Perceptions of performing bereavement follow-up 1) A rewarding conclusion of the relationship 2) An opportunity to support the family members' coping with bereavement 3) Positive to get feedback on the provided palliative care 4) Whose needs are being met?
ii) Aspects influencing perceptions of providing bereavement follow-up 1) Family members' coping and acceptance 2) Own competence, experience and coping 3) The relationship to the family member 4) Time, peace and setting priorities in the units 5) Support to the staff members 6) Clarity in format and content

Figure Legend:

Figure 1a-c. Staff members' assessment of performing bereavement follow-up versus workload, experiences and age.