Support Received by Family Members Before, at and After an Ill Person’s Death

Anna O´Sullivan  
Ersta Sköndal Bräcke University College

Anette Alvariza  
Ersta Sköndal University College

Joakim Öhlén  
University of Gothenburg

Cecilia Larsdotter  (cecilia.larsdotter@shh.se)  
Sophiahemmet University College

Research Article

Keywords: family members, support, information, communication, palliative care, end-of-life care

DOI: https://doi.org/10.21203/rs.3.rs-273795/v1

License: © This work is licensed under a Creative Commons Attribution 4.0 International License.  
Read Full License
Abstract

Background: It is widely recognised, that family members are central to care of people with advanced illness, and that support should be provided to all family members in need thereof. The aim of this study was to investigate family members’ experiences of support received during the last three months of life, at the time of death and after the death of a person with advanced illness.

Methods: A retrospective cross-sectional survey design was employed, using the VOICES(SF) questionnaire and multiple methods for data analyses. The sample consisted of 485 bereaved family members (aged: 20-90 years old, 70% women) of people who died in hospital between August 2016-April 2017.

Results: Of the family members, 58.8% reported they had received enough help and support during the illness, whereas 30.2% had not. Family members’ comments about support during the illness were mainly related to care the ill person had or had not received, rather than about support they themselves received. Of all family members, 52.8% reported having had enough support at the time of the ill person's death. Related to support at death, 14.6% reported that the imminence of death was not clear, which was described as having affected their opportunity to be with the dying person at the time of death. Of all, 25.2% had a follow-up conversation after the death, 48% did not and did not want to, and 21% had no follow-up conversation, but would have liked one. A follow-up conversation was described as helpful for the bereavement process, and disappointment was expressed when not receiving support after the death.

Conclusions: Family members’ experiences of support were partly related to whether the ill person's care needs were fulfilled. Healthcare staff expressing empathy and respect in the care of dying people and their family members were important for family members’ experiences of support. Family members’ difficulty recognising that death was imminent and the importance of healthcare staff providing them with clear information were expressed in connection with support at death. Follow-up conversations were valued by family members, especially if with a healthcare professional who was present at the time of death.

Background

It is widely recognised that family members are often central to care of people with advanced illness. During the illness period and after death, care and support should be provided to patients as well as their family members. Being a family member of a person with advanced illness can have a multidimensional impact: psychological, with increased stress and worry; physical, due to various —at times burdensome—practical care activities; social, involving limitations on social life; and financial, having to take time off work to be a caregiver and/or the absence of income for the ill person [1, 2]. Hence, support for family members is an essential part of palliative care.

Several previous studies have pointed out different types of support for family members. Psychological and emotional support is often received through some form of counselling, either individually or in
groups. Practical support can involve, for example, help with household chores or respite for the family member, if the ill person is living at home. Family members’ support needs vary and may fluctuate during the illness period and after the death of the ill person [3, 4]. International studies have shown that the support family members do or do not receive may affect their health —for example, in terms of anxiety and depression symptoms— which may result in a worse bereavement experience [5-7].

Various barriers for adequate support to family members have been found, e.g., healthcare staff feeling unprepared or lacking time to communicate. Another barrier for providing adequate support is family members and the ill person not accepting or grasping the prognosis [8, 9]. In Sweden, support available to family members of people with advanced illness varies — depending on, for example, the care setting and geographic area of residence [3, 10]. There is a sparsity of studies that investigate overall support family members received during the last period of illness of a person, at death and throughout the period after death — and it is these issues that this study aims to explore.

**Methods**

**Aim**

The aim of this study was to investigate family members’ experiences of support received during the last three months of life, at the time of death and after the death of a person with advanced illness.

**Design**

This study employed a retrospective cross-sectional survey design using The VOICES (SF) (Views of Informal Carers – Evaluation of Services) (Short Form) questionnaire, and multiple methods for data analyses.

**Setting and Sample**

The study sample consisted of adult bereaved family members of persons with advanced illness, who died in four hospitals, located in two Swedish healthcare regions, between August 2016 and April 2017. In Sweden, care at the end of life can be provided at home, in hospitals, in nursing homes and in specialized palliative care units, e.g., hospices. The deceased persons had all died in hospital but had received care in several care places and settings, in one of the healthcare regions. The hospitals were used as recruitment settings since 42% of the Swedish population die in hospital [11].

The inclusion criteria were that the deceased persons had identifiable bereaved family members; both deceased persons and bereaved family members needed to be 18 years old or older; and the deceased person had to have died from underlying causes of death (ICD-10 codes) in accordance with the Murtagh et al. [12] model: HIV/AIDS; Malignant Neoplasms (Cancer); Alzheimer’s disease, dementia and senility;
Neurodegenerative diseases; Heart diseases including cerebrovascular diseases; Respiratory diseases; Liver diseases and Renal diseases.

The questionnaires were sent to the bereaved family members four to twelve months after the death of the deceased person, which is in accordance with experiences from previous studies using VOICES (SF), in which it was concluded —after testing different time frames— that 4–12 months after death was a good time period, striking a balance between intrusion in the grieving process and avoiding the likely gradually reduction in the ability to recall over time [13-17].

The VOICES (SF) questionnaire

The VOICES (SF) is a questionnaire that retrospectively evaluates the quality of care received in several different care places, during an ill person's last three months of life, based on bereaved family members’ reports. The full version of VOICES (SF) has been translated and validated into other languages by other research groups [18-20]. The Swedish version [21] of the questionnaire is divided into domains such as Care at home; Care homes; Hospital care; and Specialized palliative care units/hospice care. It contains 75 items, initially about characteristics (e.g., age, sex, educational attainment, relationship to the deceased person), followed by, e.g., items about symptom relief, communication, involvement in decision-making, being treated with respect and dignity by care staff and satisfaction with care. The questionnaire includes structured items about help and support received during the illness, at the death of the ill person and after the death. Additionally there are open-ended questions — some in connection with the items about support and help, and three open-ended questions at the end of the questionnaire. There have been previous studies using VOICES in different patient groups and in various healthcare settings, both in cross-sectional studies and at a population level, mainly in the United Kingdom, where the questionnaire was developed [13, 17].

Study variables

Variables used to describe the characteristics of the bereaved family members were age, sex and educational level. The same variables were used for the deceased persons, with additional ones also included — namely time of illness before death, diagnosis, care place/care provider, number of care places and the relationship between the deceased person and their family member.

The variables chosen for this study were questionnaire items about the following: support during the illness; having been contacted in time to be present at the death; support from the staff at the time of death; being treated with respect by staff at the time of death; and support after the death. Five open-ended questions were also included. Of these, two were comments linked to the items about support during the illness and being treated with respect by staff at the time of death. The other three were open-ended questions in the final part of the questionnaire; one asking if the respondent would like to add
anything else about the care and support received, and two questions asking whether anything was good or bad about the care (Table 1).

**Recruitment and data collection**

Of all the patients who died in the recruitment hospitals during the study period, about 80% (n=1277) were eligible for inclusion. Based on the inclusion criteria, hospital administrators identified the deceased persons, and their bereaved family members were identified via the hospital’s patient records by one healthcare professional at each hospital (assigned to assist Author 1). Postal addresses of the bereaved family members were retrieved from publicly available databases. Written information about the study was sent, including contact information for one of the researchers (Author 1), information stating that the study was performed in cooperation with the hospital in which their family member had died and the VOICES (SF) questionnaire along with a pre-paid return envelope. The written information assured confidentiality and the right to withdraw from the study at any time without explanation. Consent was considered to have been obtained upon return of a questionnaire; no other written informed consent for participation in the study was obtained. For ethical reasons — i.e., being sensitive towards the family members who may be considered vulnerable due to bereavement and may not wish to participate— no reminders were sent.

**Characteristics of the deceased persons and their bereaved family members**

The deceased persons were between 40 and 90 years or older (64% were 80 or older) and 50,3% were men. Of the deceased persons, 72,5% had lower secondary education, 11,1% higher secondary education and 15,5% higher education. The most common underlying cause of death was heart diseases, including cerebrovascular diseases (56,3%), followed by cancers (15,8%) and respiratory diseases (15,1%) (Table 2). The participating family members were between 18 and 90 years old or older and 70,7% were women. Of the family members, 29,5% had lower secondary education, 30,5% higher secondary education and 39,4% higher education. About half (51,4%) were children of the deceased person and 34,3 % were spouses or partners. Of the deceased persons, 79,2% had been cared for at home at some point during the last three months of life, with 52% receiving care from general practitioners (GPs); 17,9% from specialised palliative home care and 36,7% received care from district- and county nurses. Furthermore, 90,7% had received hospital care, 27,4% nursing home care and 15,7% care in a specialised palliative care unit. The number of places of care during the last three months of life ranged from 1 to 4, with two places being most common (63,4%), followed by three places (20,4%), one place (12,9%) and, least commonly, four places of care (3,3%).

The characteristics of the bereaved family members who chose to answer one or more of the open-ended questions differed slightly from the total sample regarding sex (77,7% women), educational attainment
(52.2% higher education and 19.3% lower education) and the deceased person’s educational attainment (20% higher education and 67.4% lower education).

**Response rate**

The response rate was 37.9%, resulting in a total of 485 bereaved family members participating in the study. The non-responding family members’ individual characteristics (e.g., age, sex, educational attainment) were not available. The deceased persons’ profiles linked to the non-responders did not differ from the sample. The responses to the open-ended questions are presented in Figure 1.

**Analysis**

Both statistical and qualitative methods were used for data analyses (Table 1).

**Statistical analyses**

Descriptive statistical analyses were used to explore the variables derived from the questionnaire items and characteristics of the deceased persons and their family members. For statistical computations, Statistical Package for the Social Sciences (SPSS) version 21.0 (IBM Corp., Armonk, NY, USA) was used.

**Qualitative analysis**

Initially, the quantitative data was analysed, after which the open-ended responses were analysed qualitatively to deepen the understanding of the family members’ responses to the items about support received. On average, the responses were 1 or 2 sentences long, ranging from a couple of words to full pages. Moreover, there was a variety in scope of content; some were quite exhaustive stories, while others were shorter substantive responses. After excluding responses with non-relevant content, 529 responses (20 full pages of single-spaced text) were analysed. The analysis was guided by ideas inherent in interpretive description, which is a viable approach for generating knowledge applicable to clinical practice. [22]. The analysis involved both descriptive and interpretive processing of data. In line with interpretive description, the authors’ theoretical and clinical knowledge—together with knowledge gained from previous studies—was used for the present study e.g. in the study design and analysis of data. Initially, with the study aim in mind, all the open-ended responses were read to obtain an overall picture. The responses were read again in the context of the family members’ varied responses to the items about support, to discover patterns and deepen the understanding of the quantitative responses. Thereafter, the text was broadly coded, identifying meaningful content and variations of contextual descriptions of support, which were organised into patterns of experiences. The patterns were then read again and interpreted through a process of asking questions such as “what is the underlying meaning of this?” The descriptions and interpretations of the text were continuously discussed and revised within the research group for clarification and further development of the analysis.
Results

Family members’ experiences of support received—during the illness, at death and after the death of a person—were varied. The results are presented under three headings: help and support during the illness period; circumstances and support at the time of death; and follow-up conversation and support received after death.

Help and support during the illness period

Of the bereaved family members, more than half (58.8%) reported that they got as much help and support as they wanted during the illness period. However, about a third reported that they did not get enough help and support (Table 3).

Being supported related to the fulfilment of care needs

Family members’ reports rarely mentioned experiences of actual help and support they themselves received during the illness period. Instead, many family members had written about the care that the ill person did or did not receive, and whether care needs were fulfilled or not seemed to have been the main focus for family members’ reports regarding experiences of help and support they received during the illness period. For example, family members described how the ill person had been denied admission to a nursing home or had been discharged without a care plan after an emergency visit to the hospital. This was described as a disappointment with healthcare and the process of decision-making process regarding care level needs. One family member wrote:

My 91-year-old father-in-law needed help with pretty much everything. He could walk a few steps with a walker indoors but had repeatedly fallen and had to go to hospital urgently. In January, an application for a place in a care home was sent, but it was rejected on the grounds that he could get the help he needed at home... Had he been given a place and given help and supervision, then he would probably not have died in February. He died after a fall at home. [Daughter-in-law]

Furthermore, family members described lack of care or insufficient care, e.g., when the ill person had been cared for at home without the right level of care and supervision, which led to frequent emergency visits with long waiting times:

There were many hospital admissions in the last year when his COPD deteriorated. It was pretty disruptive; he was often sent back home. The preparedness in emergency situations was good. I had wished for something in between shorter hospital stays and sent home to no care at all. More home care and follow-up at home. [Son]

Family members wrote about the importance of professionals in the position of deciding on care level for the ill person also listening to the family members’ views on care needs. For example, care was sometimes not provided since the ill person did not want care, even though the family member thought
that it was needed: “My mother did not want help but was in great need of it.” [Daughter] This created
stress for the family member who could not be close at hand all the time. This was especially stressful
when the ill person lived alone and had a history of many fall injuries or a dementia diagnosis. A
daughter summarised this situation, outlining: “… the difficulty and complexity of being a family member
balanced with the ‘personal integrity’ of the patient.”

Furthermore, family members described how they had to act as co-ordinator for the ill person's care, due
to lack of communication and cooperation between health care providers. Family members described
feeling as if they had to make sure that things were being done. This raised questions about who actually
had the primary responsibility for care — the healthcare providers, the patient or the family members. A
daughter wrote:

The coordination, communication, responsibility and feedback

from homecare services that have no idea who has been or what

has been done during the weekends... The outsourced care at the

weekend cannot be contacted. When they call me, they do not know what medicine my demented mother

should have!!

And you never met the same staff. [Daughter]

Circumstances and support at the time of death

Being contacted in time

Of the bereaved family members, 49,5% reported that they had been contacted in time to be with the ill
person at death. For 7,8% of the family members, this was not the case, and for another 14,6% it was not
clear how soon death would come (Table 4).

Family members described that they had appreciated the opportunity to say a last goodbye. They were
also grateful that the ill person did not have to die without any family present. Not having been informed
about the ill person's deterioration and, hence missing the opportunity to be there was described as
upsetting: “He died in the dining room, no one was with him, he had been unwell...no one knew when he
died”. [Wife]

Family members also reported how difficult it was to understand when the end would come, i.e., they had
not realised how close death was and were not prepared for it to come as soon as it did: “The end was
near but I did not realise”. [Niece]

Being supported and treated with respect by staff at the time of death
More than half (52.8%) of the bereaved family members reported that they had received enough help and support from the staff at the time of the ill person’s death. Of the participants, 27.6% experienced having received help and support to some extent and another 12.4% reported ‘No, not at all’ with regard to getting enough help and support at the time of death (Figure 2). The majority of family members (85.8%) reported that they had been treated with respect by the staff at the time of the death (Figure 3).

Many comments were about the staff’s approach around the time of death. To have been given space and time to mourn, and to have been shown empathy, e.g., through a hug, were described as supportive and respectful activities. In addition, family members appreciated staff showing respect by caring for the deceased person by cleaning, dressing and preparing the person and making the room look nice with flowers or lit candles: “They asked if we needed anything, such as sleeping pills, gave information about counselling and made the room nice with candlelight”. [Wife] However, some family members also described negative experiences and lack of support, e.g., staff mostly handling practical matters rather than showing empathy or expressing their condolences: “They asked if we wanted him autopsied”. [Friend] Other examples were family members only being told what forms to fill out and by what time they had to pack up the deceased person’s belongings and leave the room.

**Follow-up conversation and support received after death**

After the death of the ill person, around a quarter (25.2%) of the family members had spoken to someone from healthcare, social services or bereavement services about their feelings. About a fifth (21.0%) had not spoken to any of these, but would have liked to do so, whereas 48% had not spoken to anyone and did not want to (Table 5).

Family members expressed disappointment in not receiving support after the death, e.g., not being offered support at all or not being contacted despite having been told someone would call — or having been given a number to call, but not getting an answer when they did call. Some described how they had spoken to a counsellor, a nurse, a physician, staff from homecare services or nursing home staff, and others reported having had support from a priest, the church or bereavement groups. A positive experience of a follow-up conversation with someone from healthcare after the death was described as helpful for the bereavement process:

They called after about 6–8 weeks to see how we, the siblings, were. Absolutely superb way of working!! We have had the opportunity to come and talk to the physician afterwards and got explained what we wondered about the death of our mother. [Daughter]

Family members described wishing to have had a conversation with a healthcare professional who was present at the death and who could have answered their questions. They also described having had a follow-up conversation, but with the ‘wrong’ person and had then not had their questions answered, e.g., regarding the circumstances at the time of death: “I received a phone call from a nurse at the ward where my father passed away. When I asked how he was before we arrived at the hospital, I got no answer. It
was not documented in his file according to the nurse”. [Daughter] This left the family members wondering and grudging about how the ill person had been at the end.

**Discussion**

In this study, the results show appreciative reports about the support family members received during the last three months of an ill person’s life, at the time of the death, and after the death. However, the results also show that the support was not optimal for all — about a third reported that they had not received enough help and support during the illness and only a quarter had a follow-up conversation after the death. Around half of the family members reported having had enough support at the time of the ill person’s death. In addition, the imminence of death was not clear for about 15% of family members, which was also described as having affected the opportunity for them to be with the dying person at the time of death.

The majority of family members reported that they received enough help and support during the deceased person's illness — slightly higher than in a previous UK nationwide population study using the VOICES [13]. In the present study, family members’ reports about help and support received during the illness period seemed to have been focused on the fulfilment of the ill person's care needs. An example was family members reporting feeling disappointed when the ill person was not granted a place in a nursing home or when the care at home was not considered to be sufficient.

Unfulfilled care needs were reported to have resulted in frequent visits to the hospital emergency room. There are several possible factors contributing to why the ill person did not receive the care needed. Firstly, it might be a question of care availability. In 2018, 40% of Sweden's municipalities reported that they had a shortfall of nursing home beds [23]. In line with this, reports have shown that nursing home bed numbers have decreased by a quarter since the year 2000, without being replaced by increased homecare services. Instead, an increase in informal caregiving by family members or friends has been seen [2]. Other contributing factors could be the difficulty in deciding on an adequate level of care and knowing in advance how continued care in the ill person's home will work. For example, regarding discharge from hospital, it has been shown that several aspects are important, namely the discharge process [24, 25], the support available in the care place to which the person is discharged [26, 27] and follow-up after discharge [25, 28]. Care planning for ill people is also complicated by the different organisational structures and responsibilities of care providers. Care planning can be improved and readmission to hospital prevented by the use of Advanced Care Planning (ACP) [27, 29]. Furthermore, the assessment of family members’ needs for support when caring for the ill person at discharge and at home after discharge may prevent the care at home from failing as well as re-admission to hospital [30].

In Sweden, home care and most forms of care for older people (including care in nursing homes) are regulated by the Social Services Act, and managed by the municipalities, whereas medical care needs are regulated by the Health and Medical Care Act and provided by different general or specialist care providers. This split in regulations and responsibility for care likely complicates the planning and delivery
of care at the end of life. Further follow up by the municipality (through social services or home care services) and primary care after discharge could improve the discharge from hospital, and could also potentially prevent hospital re-admissions [24].

In the present study, family members reported care not being delivered, even though the family member thought it necessary, since the ill person did not wish to receive care. This was also shown in a study by Tarberg’s et al., in which family members described how they had to provide burdensome informal care, since the ill person did not accept formal care [31]. Diverse, contrasting views regarding care needs between the ill person, family members and staff can result in the ill person ending up with care that they do not want [24]. Differing views on the part of the ill person and family members about care needs could have been partly related to the ill person struggling with being at the end of life and in need of care — e.g., trying to make sense of dying and accepting inevitable death [32, 33]. A way to support the ill person to grasp the situation and accept help is by healthcare staff supporting family members to initiate and strive for a more open communication about the illness, prognosis and individual wishes for the end-of-life care [34].

The importance of being informed of imminent death by healthcare has been previously reported, as has family members’ difficulty in seeing that the end is near [35, 36]. In the present study, family members reported that they wished healthcare staff had informed them that the ill person would die soon, to have given them a chance to be present. Family members not realising that the death was imminent could partly be due to them being unprepared for death and not informed enough to understand the process of dying, or as a result of healthcare staff not being clear enough in their communication about death, e.g., by using euphemisms, like “her time is near” [35, 37, 38]. In line with this, previous research has shown that healthcare staff often feel uneasy discussing death and dying with patients and family members. There is also the difficulty for healthcare staff with regard to sharing information about a poor prognosis and imminent death if the ill person or family members are not open to receiving such information [36, 39]. Family members may need help interpreting information from healthcare staff, to appreciate how close death really is [35, 37, 38]. In this and previous studies, family members expressed the importance of, and gratefulness for, being able to spend the final moments with the dying person and the disappointment associated with not being able to do so [35, 38].

About half of the bereaved family members in this study reported that they got enough help and support from the staff at the time of the ill person’s death, which is slightly lower than reported in a UK national study [13]. Furthermore, around 12% of the family members reported not having received enough help and support at all at the time of the ill person’s death. Circumstances contributing to this could be related to family members’ reports of how they would have liked the staff to have shown more empathy and acknowledged their loss — e.g., through expressing their condolences or a gesture like a hug in connection with the death. In previous research, family members’ requests for more compassionate, sensitive and empathetic approaches on the part of healthcare staff at the end of life and at the time of death have been reported [5, 35, 40, 41].
A quarter of the family members had —by the time of study participation— spoken to someone from healthcare, social services or bereavement services about their feelings regarding the deceased person’s illness and death, and this was described as helpful in their grief. This is low compared to a nationwide UK study, in which twice as many bereaved family members had a follow-up conversation [13]. It is also low compared to the 67% of bereaved family members that were offered follow-up conversations, registered by healthcare providers in the national Swedish Register for palliative care in 2019 [42]. In the present study, a fifth of the family members had not spoken to anyone but would have liked to. Follow-up conversations may facilitate the bereavement process, and the lack of one may have the opposite effect [5, 7], with a risk of resulting in prolonged grief [43, 44].

Limitations

The response rate to the survey was rather low (37.9%) and could potentially have been improved by reminders and repeated mail outs. It was, however, an ethical choice not to do so, in order not to distress or put pressure on the bereaved family members. Nevertheless, there was a good level of engagement from those who did participate; more than half (56%) chose to leave responses to the open-ended questions. Additionally, the quantity and quality of the qualitative data was considered sufficient to investigate the study aim. The interpretations and descriptions based on the open-ended responses were continuously discussed within the research group and these have been supplemented by participant’s quotations to confirm the interpretations. Views on the use of open-ended questions in surveys are mixed and so is the choice of analysis for these. Responses to open-ended questions can help to explain, illuminate or expand upon specific quantitative questions. However, methodological literature does not provide much guidance about ways of analysing open-ended question data [45].

Of the participating family members in this study, 70.7% were women. The majority were children of the deceased persons, followed by spouses. In Sweden, it is more common for women to provide informal care than it is for men to do so [2, 46], which might partly explain the higher number of women invited to participate in this study. This lack of gender balance could be considered a limitation. Another potential limitation is that the whole sample consisted of people who had died in hospital. Hospital is the most common place of death in Sweden [11] and people who die in hospital commonly have several other places of care during the final stages of their illness trajectory, before dying in the hospital. However, this study does provide new and important knowledge about the support family members received during a person’s illness, at death and after the death.

Conclusions And Implications

In this study, family members’ experiences of support were partly related to whether the ill person’s care needs were fulfilled. The study showed that healthcare staff expressing empathy and respect in the care of dying people and their family members were important for family members’ experiences of support. The family members’ difficulty recognising that death was imminent and the importance of healthcare staff providing them with clear information were both factors expressed in connection with family
members’ experiences of support at death. Finally, the study showed that follow-up conversations were valued by family members, especially if with a healthcare professional who was present at the time of death. Clearer guidelines regarding communication about end-of-life issues and support, and targeted training for healthcare staff, may improve family members’ experiences of support during a person’s illness, at the time of death and after death.

Declarations

Ethical approval and consent to participate

The Regional Ethical board in Stockholm, Sweden, has approved this study (Approval number: 2017/265-31). With the questionnaire, the participants received written information about the study and were informed that the data would be completely confidential and that they could withdraw from the study at any time without any explanation. A returned questionnaire was considered as consent; no other written informed consent for participation in the study was provided.

Consent for publication

Not applicable.

Availability of data and materials

The datasets generated and/or analysed during the current study are not publicly available, but are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

Ersta Sköndal Bräcke University College; Sven and Dagmar Salén’s foundation; Ulrica Croné’s foundation and The Swedish network - Nurses for Palliative Nursing Care.

Author’s contributions

AO, AA, JÖ and CL planned the study. AO analysed the quantitative data statistically and AO, AA, JÖ and CL interpreted the results. AO, AA, JÖ and CL analysed the qualitative data, and the data was continuously revised until a consensus was reached. AO wrote the first manuscript draft and AA, JÖ and CL carried out critical revisions. All authors approved the final version.
Acknowledgements

We would like to thank the hospitals involved as well as the family members for all their co-operation.

Confirmatory statements

We confirm that all methods were carried out in accordance with relevant guidelines and regulations. We further confirm that informed consent was considered to have been obtained upon return of a questionnaire; no other written informed consent for participation in the study was obtained.

Author’s information

Palliative research centre, Department of Healthcare sciences, Ersta Sköndal Bräcke University College Stockholm, Sweden; Capio Palliative Care Unit, Dalen Hospital, Stockholm, Sweden; Centre for Person-Centered Care, University of Gothenburg, Gothenburg, Sweden; Institute of Health and Care Sciences, Sahlgrenska Academy at the University of Gothenburg, Gothenburg, Sweden; Palliative Centre, Sahlgrenska University Hospital, Gothenburg, Sweden; Department of Nursing science, Sophiahemmet University, Stockholm, Sweden.

References

1. Hudson P, Remedios C, Zordan R, Thomas K, Clifton D, Crewdson M, Hall C, Trauer T, Bolleter A, Clarke DM et al: Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. *Journal of palliative medicine* 2012, 15(6):696-702.

2. Ulmanen P, Szebehely M: From the state to the family or to the market? Consequences of reduced residential eldercare in Sweden. *International Journal of Social Welfare* 2015, 24(1):81-92.

3. National Board of Health and Welfare (NBHW): Palliative care at the end of life: Summary and improvement areas (In Swedish: Palliativ vård i livets slutskede: Sammanfattning med förbättringsområden). 2016.

4. Payne S: White paper on improving support for family carers in palliative care: Part 1: Recommendations from the European association for palliative care (EAPC) task force on family carers. *European Journal of Palliative Care* 2010, 17:238-245.

5. Holdsworth LM: Bereaved carers’ accounts of the end of life and the role of care providers in a ‘good death’: A qualitative study. *Palliative Medicine* 2015, 29(9):834-841.

6. Payne S, Hudson P, Grande G, Oliiviere D, Tishelman C, Pleschberger S, Firth P, Ewing G, Hawker S, Kerr C: White Paper on Improving Support for Family Carers in Palliative Care, Part 2. *European Journal of Palliative Care* 2010, 17(6):286-290.

7. Morris SEP, Block SDMD: Adding Value to Palliative Care Services: The Development of an Institutional Bereavement Program. *Journal of Palliative Medicine* 2015, 18(11):915-922.
8. Brighton LJ, Bristowe K: *Communication in palliative care: talking about the end of life, before the end of life*. *Postgraduate medical journal* 2016, 92(1090):466-470.

9. Beckstrand RL, Collette J, Callister L, Luthy KE: *Oncology Nurses' Obstacles and Supportive Behaviors in End-of-Life Care: Providing Vital Family Care*. *Oncology Nursing Forum* 2012, 39(5):398-406.

10. National Board of Health and Welfare (NBHW): *National guidelines for palliative care [in Swedish]*. In. Sweden; 2013.

11. Håkanson C, Öhlén J, Morin L, Cohen J: *A population-level study of place of death and associated factors in Sweden*. *Scand J Public Health* 2015, 43(7):744-751.

12. Murtagh FE, Bausewein C, Verne J, Groeneveld EI, Kaloki YE, Higginson IJ: *How many people need palliative care? A study developing and comparing methods for population-based estimates*. *Palliat Med* 2014, 28(1):49-58.

13. Hunt KJS N, Richardson, A. Addington-Hall, J.: *Voices re-design and testing to inform a national end-of-life care survey. Final report for the department for health*. UK: University of South Hampton; 2011.

14. Young AJ, Rogers A, Addington-Hall JM: *The quality and adequacy of care received at home in the last 3 months of life by people who died following a stroke: a retrospective survey of surviving family and friends using the Views of Informal Carers Evaluation of Services questionnaire*. *Health & Social Care in the Community* 2008, 16(4):419-428.

15. Addington-Hall JM, O’Callaghan AC: *A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in in-patient hospices compared with hospitals, from the perspective of bereaved relatives: Results from a survey using the VOICES questionnaire*. *Palliat Med* 2009, 23(3):190-197.

16. Young AJ, Rogers A, Dent L, Addington-Hall JM: *Experiences of hospital care reported by bereaved relatives of patients after a stroke: a retrospective survey using the VOICES questionnaire*. *J Adv Nurs* 2009, 65(10):2161-2174.

17. Hunt KJ, Richardson A, Darlington AE, Addington-Hall JM: *Developing the methods and questionnaire (VOICES-SF) for a national retrospective mortality follow-back survey of palliative and end-of-life care in England*. *BMJ Support Palliat Care* 2017, 9(1):e5.

18. Hughes R, Saleem T, Addington-Hall J: *Towards a culturally acceptable end-of-life survey questionnaire: a Bengali translation of VOICES*. *International journal of palliative nursing* 2005, 11(3):116-123.

19. Ross L, Neergaard MA, Petersen MA, Groenvold M: *Measuring the quality of end-of-life care: Development, testing, and cultural validation of the Danish version of Views of Informal Carers’ Evaluation of Services–Short Form*. *Palliative Medicine* 2018, 32(4).

20. Strupp J, Hanke G, Schippel N, Pfaff H, Karbach U, Rietz C, Voltz R: *Last Year of Life Study Cologne (LYOL-C): protocol for a cross-sectional mixed methods study to examine care trajectories and transitions in the last year of life until death*. *BMJ open* 2018, 8(4).
21. O’Sullivan A, Öhlén J, Alvariza A, Håkanson C: Adaptation and validation of the VOICES (SF) questionnaire - for evaluation of end-of-life care in Sweden. Scandinavian journal of caring sciences 2017.

22. Thorne SE: Interpretive description : qualitative research for applied practice, Second edition. edn. New York, NY :: Routledge; 2016.

23. National Board of Health and Welfare (NBHW): Vård och Omsorg av Äldre - Lägesrapport 2019 (Healthcare and Care of the Elderly - Status Report 2019). 2019.

24. Rydeman I, Tömkvist L, Agreus L, Dahlberg K: Being in-between and lost in the discharge process—An excursus of two empirical studies of older persons’, their relatives’, and care professionals’ experience. International Journal of Qualitative Studies on Health and Well-being 2012, 7(1):19678.

25. National Board of Health and Welfare (NBHW): Om övergångar mellan sluten vård och öppen vård och omsorg. 2017.

26. Fogg C, Griffiths P, Meredith P, Bridges J: Hospital outcomes of older people with cognitive impairment: An integrative review. International Journal of Geriatric Psychiatry 2018, 33(9):1177-1197.

27. Chan HY-L, Ng JS-C, Chan K-S, Ko P-S, Leung DY-P, Chan CW-H, Chan L-N, Lee IF-K, Lee DT-F: Effects of a nurse-led post-discharge advance care planning programme for community-dwelling patients nearing the end of life and their family members: A randomised controlled trial. International journal of nursing studies 2018, 87:26-33.

28. Lewis E, Samperi S, Boyd-Skinner C: Telephone follow-up calls for older patients after hospital discharge. Age and ageing 2017, 46(4):544-546.

29. Slatyer S, Toye C, Popescu A, Young J, Matthews A, Hill A, Williamson DJ: Early re-presentation to hospital after discharge from an acute medical unit: perspectives of older patients, their family caregivers and health professionals. Journal of Clinical Nursing 2013, 22(3-4):445.

30. Ewing G, Austin L, Jones D, Grande G: Who cares for the carers at hospital discharge at the end of life? A qualitative study of current practice in discharge planning and the potential value of using The Carer Support Needs Assessment Tool (CSNAT) Approach. Palliative medicine 2018, 32(5):939-949.

31. Tarberg AS, Kvångarsnes M, Hole T, Thronæs M, Madssen TS, Landstad BJ: Silent voices: Family caregivers’ narratives of involvement in palliative care. Nursing Open 2019, 6(4):1446-1454.

32. Sellars M, Clayton JM, Morton RL, Luckett T, Silvester W, Spencer L, Pollock CA, Walker RG, Kerr PG, Tong A: An Interview Study of Patient and Caregiver Perspectives on Advance Care Planning in ESRD. American journal of kidney diseases : the official journal of the National Kidney Foundation 2018, 71(2):216-224.

33. Kyota A, Kanda K: How to come to terms with facing death: a qualitative study examining the experiences of patients with terminal Cancer. BMC Palliative Care 2019, 18(1):33.

34. Røen I, Stifoss-Hanssen H, Grande G, Brenne AT, Kaasa S, Sand K, Knudsen AK: Resilience for family carers of advanced cancer patients-how can health care providers contribute? A qualitative interview
study with carers. *Palliative medicine* 2018, 32(8):1410-1418.

35. Odgers J, Fitzpatrick D, Penney W, Shee AW: **No one said he was dying: Families’ experiences of end-of-life care in an acute setting**. *Australian Journal of Advanced Nursing, The* 2018, 35(3):21-31.

36. Richards N, Ingleton C, Gardiner C, Gott M: **Awareness contexts revisited: indeterminacy in initiating discussions at the end-of-life**. *Journal of Advanced Nursing* 2013, 69(12):2654-2664.

37. Shan M, Swami N, Pope A, Rodin G, Hannon B, Nissim R, Hales S, Zimmermann C: "I didn't want to be in charge and yet I was": Bereaved caregivers' accounts of providing home care for family members with advanced cancer. *Psycho - Oncology* 2018, 27(4):1229-1236.

38. Steinhauser KE, Voils CI, Bosworth H, Tulsky JA: **What constitutes quality of family experience at the end of life? Perspectives from family members of patients who died in the hospital**. *Palliative & supportive care* 2015, 13(4):945-952.

39. Noble H, Price JE, Porter S: **The challenge to health professionals when carers resist truth telling at the end of life: a qualitative secondary analysis**. *Journal of Clinical Nursing* 2015, 24(7-8):927-936.

40. Clark K: **Care at the Very End-of-Life: Dying Cancer Patients and Their Chosen Family's Needs**. *Cancers* 2017, 9(2).

41. Hajradinovic Y, Tishelman C, Lindqvist O, Goliath I: Family members’ experiences of the end-of-life care environments in acute care settings - a photo-elicitation study. *International journal of qualitative studies on health and well-being* 2018, 13(1):1511767.

42. The Swedish Register of Palliative Care: **Annul Report from the Swedish Register of Palliative Care**. In.; 2019.

43. Shear MK, Ghesquiere A, Glickman K: **Bereavement and Complicated Grief**. *Current Psychiatry Reports* 2013, 15(11):406.

44. Guldin M-b, Vedsted P, Zachariae R, Olesen F, Jensen AB: Complicated grief and need for professional support in family caregivers of cancer patients in palliative care: a longitudinal cohort study. *Supportive Care in Cancer* 2012, 20(8):1679-1685.

45. O'Cathain A, Thomas KJ: "**Any other comments?**" Open questions on questionnaires – a bane or a bonus to research? *BMC Medical Research Methodology* 2004, 4(1):25.

46. Ulmanen P: **Working Daughters: A Blind Spot in Swedish Eldercare Policy**. *Social Politics: International Studies in Gender, State & Society* 2013, 20(1):65-87.

**Tables**

Table 1. Study variables and analyses
| Items                                                                 | Response alternatives                                                                                              | Analysis                                      |
|----------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------|-----------------------------------------------|
| Overall, do you feel that you and your family got as much help and  | Yes, we got as much support as we needed/yes, we got some support, but not as much as we wanted/no, although we   | Quantitative descriptive                      |
| support from health and social services as you needed when caring    | tried to get more help/no, but we did not try to get more help/we did not need help/missing                       |                                               |
| for him/her?                                                        |                                                                                                                  |                                               |
| Please feel free to make comments in the space below                 | Open-ended question                                                                                                | Qualitative - interpretive descriptive       |
| Were you contacted soon enough to give you time to be with him/her   | Yes/no/I was already there/it was not clear he/she was going to die soon/I couldn't have got there anyway/I was   | Quantitative descriptive                      |
| before he/she died?                                                 | not contacted/missing                                                                                           |                                               |
| Were you or his/her family given enough help and support by the      | Yes, definitely/yes, to some extent/no, not at all/don't know/missing                                            | Quantitative descriptive                      |
| healthcare team at the actual time of his/her death?                 |                                                                                                                  |                                               |
| Were you or his/her family treated with respect by the staff after   | Yes/no/don't know/does not apply, I had no contact with the staff/missing                                         | Quantitative descriptive                      |
| he/she had died?                                                    |                                                                                                                  |                                               |
| Please feel free to make comments in the space below                 | Open-ended question                                                                                                | Qualitative - interpretive descriptive       |
| Since he/she died, have you talked to anyone from health and social  | Yes/no, but I would have liked to/no, but I did not want to anyway/unsure/missing                                  | Quantitative descriptive                      |
| services, or from a bereavement service, about your feelings about    |                                                                                                                  |                                               |
| his/her illness and death?                                           |                                                                                                                  |                                               |
| Please use the space below if there is anything else you would like  | Open-ended question                                                                                                | Qualitative - interpretive descriptive       |
| to tell us about the care and support you received                   |                                                                                                                  |                                               |
| What, if anything, was good about the care?                         | Open-ended question                                                                                                | Qualitative - interpretive descriptive       |
| What, if anything, was bad about the care?                          | Open-ended question                                                                                                | Qualitative - interpretive descriptive       |

*No response options or missing responses were excluded from the analyses.*
Table 2. Characteristics of the deceased persons and their family members
|                                | Deceased persons | Family members |
|--------------------------------|------------------|----------------|
|                                | %    | n    | %    | n    |
| **Sex (missing = 0/0)** b      |      |      |      |      |
| Male                           | 50.3 | (244)| 29.3 | (142)|
| Female                         | 49.7 | (241)| 70.7 | (343)|
| **Age (missing = 1/8)** b      |      |      |      |      |
| 18–39                          | 2.4  | (12) |      |      |
| 40–59                          | 3.5  | (17) | 29.1 | (141)|
| 60–69                          | 8.9  | (43) | 31.3 | (152)|
| 70–79                          | 23.1 | (112)| 22.9 | (111)|
| 80–89                          | 36.7 | (178)| 11.3 | (55 )|
| 90+                            | 27.6 | (134)| 1.2  | (6)  |
| **Educational attainment (Missing = 5/3)** b |      |      |      |      |
| Lower secondary education      | 72.4 | (351)| 29.5 | (143)|
| Higher secondary education     | 11.1 | (54) | 30.5 | (148)|
| Higher education               | 15.5 | (75 )| 39.4 | (191)|
| **Underlying cause of death 1** c |      |      |      |      |
| Cognitive diseases             | 1.0  | (4)  |      |      |
| Neurodegenerative diseases     | 1.0  | (4)  |      |      |
| Liver diseases                 | 1.5  | (6)  |      |      |
| Renal diseases                 | 9.4  | (38) |      |      |
| Respiratory diseases           | 15.1 | (61) |      |      |
| Cancer                         | 15.8 | (64) |      |      |
| Heart diseases (incl. cerebrovasular) | 56.3 | (228)|      |      |
| **Underlying cause of death 2** c |      |      |      |      |
| HIV/Aids                       | 0.3  | (1)  |      |      |
| Liver diseases                 | 0.9  | (3)  |      |      |
| Neurodegenerative diseases     | 1.2  | (4)  |      |      |
| Disease                                      | Percentage | N  |
|----------------------------------------------|------------|----|
| Cognitive diseases                           | 3.5        | (12)|
| Renal diseases                               | 4.4        | (15)|
| Respiratory diseases                         | 10.2       | (35)|
| Cancer                                       | 15.2       | (52)|
| Heart diseases (incl. cerebrovasular)        | 64.3       | (220)|

| Length of illness before death (Missing = 6) |
|---------------------------------------------|
| Sudden death                                | 5.4        | (26)|
| < 24 h                                      | 2.1        | (10)|
| 24 h – 1 week                               | 10.7       | (52)|
| 1 week – 1 month                            | 13.0       | (63)|
| 1 month – 6 months                          | 14.8       | (72)|
| 6 months – 1 year                           | 10.3       | (50)|
| 1 year or more                              | 42.5       | (206)|

| Relationship (missing = 4) |
|------------------------------|
| Spouse                       | 34.5         | (166)|
| Child                        | 51.8         | (249)|
| Other ^d                     | 13.7         | (66)|

^a Column percentage displayed

^b Missing = 0/0 shows the number of missing cases for deceased persons/bereaved family members

^c Underlying causes of death according to Murtagh’s (2014) model for potential palliative care needs

^d E.g., parent, sibling, friend

Table 3. Overall, do you feel that you and your family got as much help and support from the health and social services as you needed when caring for him/her?
| Response                                                                 | N  | %   |
|-------------------------------------------------------------------------|----|-----|
| Yes, we got as much support as we wanted                                | 285| 58.8|
| Yes, we got some support, but not as much as we wanted                  | 91 | 18.8|
| No, although we tried to get more help                                  | 27 | 5.6 |
| No, but we did not ask for more help                                    | 28 | 5.8 |
| We did not need any help                                                 | 33 | 6.8 |
| Missing                                                                 | 21 | 4.3 |

Table 4. Were you contacted soon enough to give you time to be with him/her before he/she died?

| Response                                                                 | N  | %   |
|-------------------------------------------------------------------------|----|-----|
| Yes                                                                     | 240| 49.5|
| No                                                                      | 38 | 7.8 |
| I was already there                                                     | 88 | 18.1|
| It was not clear that he/she was going to die soon                      | 71 | 14.6|
| I could not have come anyway                                            | 16 | 3.3 |
| I was not contacted                                                     | 14 | 2.9 |
| Missing                                                                 | 18 | 3.6 |

Table 5. Since he/she died, have you spoken to anyone from healthcare, social services or bereavement services about your feelings about his/her illness and death?
| Response                              | N  | %   |
|--------------------------------------|----|-----|
| Yes                                  | 122| 25.2|
| No, but I would have liked to        | 102| 21.0|
| No, I didn’t want to anyway          | 233| 48.0|
| Not sure                             | 15 | 3.1 |
| Missing                              | 13 | 2.7 |