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Clinical paper

Grief reactions in relation to professional and social support among family members of persons who died from sudden cardiac arrest: A longitudinal survey study

Nina Carlsson\textsuperscript{a,}\textsuperscript{*}, Anette Alvariza\textsuperscript{b,}\textsuperscript{c,}\textsuperscript{1}, Lena Axelsson\textsuperscript{d,}\textsuperscript{2}, Anders Bremer\textsuperscript{a,}\textsuperscript{e,}\textsuperscript{3}, Kristofer Arestedt\textsuperscript{a,}\textsuperscript{f,}\textsuperscript{4}

Abstract

Background: The loss of a close person from sudden cardiac arrest (CA) leaves family members at risk of developing grief reactions such as symptoms of prolonged grief, anxiety, depression, and posttraumatic stress. The aim was to describe longitudinal variations in grief reactions and its association with professional and social support among bereaved family members after a close person’s death from sudden CA.

Methods: This longitudinal multimethod survey included 69 bereaved family members who completed a questionnaire 6 and 12-months after the CA, including the Prolonged Grief Disorder-13, Hospital Anxiety and Depression Scale, PTSD Checklist for DSM-5, and Multidimensional Scale of Perceived Social Support. Qualitative data were collected by open-ended questions. Quantitative data was analyzed using Wilcoxon signed-rank test and linear regression analysis while written comments were analyzed using qualitative content analysis.

Results: The median age was 62 years, 67\% were women, and 38\% had been present during the resuscitation attempts. Using the cut-off scores at the 6- and 12-month assessments respectively, 14\% and 17\% reported symptoms of prolonged grief, 32\% and 26\% symptoms of anxiety, 14\% and 9\% depression, and 4\% and 1\% posttraumatic stress. Professional and social support at the 6-month assessment were significantly associated with symptoms of prolonged grief, anxiety, depression, and/or posttraumatic stress at the 12-month assessments but could not predict any changes in the grief reactions.

Conclusions: Family members’ grief reactions point to the importance of proactive and available support over time to meet family members’ needs.

Keywords: Anxiety, Cardiac arrest, Depression, Posttraumatic stress, Prolonged grief, Social support

Introduction

Cardiac arrest (CA) is a severe condition associated with high mortality,\textsuperscript{1-3} and this leaves many family members in grief after the sudden loss of a close person. Most people have resilience to cope with such loss,\textsuperscript{4} but it is of importance to recognize that the suddenness of death, can increase the risk of developing complicated grief reactions\textsuperscript{5} such as symptoms of prolonged grief,\textsuperscript{6,7} anxiety,\textsuperscript{8,9} depression,\textsuperscript{7,10} and posttraumatic stress.\textsuperscript{7,10}

Family members often have post resuscitation care needs such as organized professional support in terms of information and emotional support.\textsuperscript{11,12} However, studies show that health care professionals lack the competence to adequately meet family members’

\textsuperscript{*} Corresponding author at: Faculty of Health and Life Sciences, Linnaeus University, SE-39182 Kalmar, Sweden.

E-mail addresses: nina.carlsson@lnu.se (N. Carlsson), anette.alvariza@mchs.se (A. Alvariza), lena.axelsson@shh.se (L. Axelsson), anders.bremer@lnu.se (A. Bremer), kristofer.arestedt@lnu.se (K. Arestedt).

\textsuperscript{1} Present address: Department of Health Care Sciences/Palliative Research Centre, Marie Cederschiöld University Box 11189, SE-10061 Stockholm, Sweden.

\textsuperscript{2} Present address: Department of Nursing Science, Sophiahemmet University, Box 5605, SE-114 86 Stockholm, Sweden.

\textsuperscript{3} Present address: Faculty of Health and Life Sciences, Linnaeus University, SE-35195 Växjö, Sweden.

\textsuperscript{4} Present address: Faculty of Health and Life Sciences, Linnaeus University, SE-39182 Kalmar, Sweden.

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reactions at the time of resucitation attempts and death. Social support from friends and family is also needed and found to be of importance with the potential to reduce the incidence of complicated grief reactions. Even though the conceptualisation of social support varies, it seems closely connected to the possibility to talk with family members and friends about one’s feelings and what has happened. Barriers to optimal social support can thus be connected to problems in communication and to feelings of not being understood.

Although professional and social support is considered important, little is known about its relation to grief reactions in bereaved family members to persons who die from sudden CA. A review study about social support in people bereaved by sudden or violent causes of death concluded that social support is associated with less severe grief reactions. The review did not include any study about CA, but recent results from our research group shows that both professional and social support were associated with grief reactions such as symptoms of prolonged grief, anxiety, depression, and/or posttraumatic stress 6 months post CA. However, no study has investigated these associations over longer time periods even though the family members' support needs are likely to change. Hence, the aim was to describe longitudinal variations in grief reactions and its association with professional and social support among bereaved family members after a close person’s death from sudden CA.

Methods

Design
This longitudinal multimethod survey study used both quantitative and qualitative data collected 6 and 12-month post CA. Data was taken from a larger research project about grief reactions among bereaved family members due to death from sudden CA. Data were collected between September 2018 and January 2021. In the present study, only family members who completed the 12-months assessment were included. Approval was granted from the Regional Ethical Review Board in Linköping, Sweden (No. 2017/525–31).

Sample and procedure
The included family members were 18 years or older and had lost an adult family member to sudden CA, in-hospital or out-of-hospital, where cardiopulmonary resuscitation attempts had been initiated. The CA should also be caused by heart or lung disease. Further, family members had to understand Swedish to be included. Family member was defined according to Whall’s definition as two or more individuals functioning in a way that they perceive as a family. Thus, not necessarily connected by blood ties or by law.

A regional part of the Swedish Register of Cardiopulmonary Resuscitation (https://shlr.registercentrum.se), in south-eastern Sweden, was screened to identify persons who had died from CA. Deceased persons with a documented Do Not Resuscitate order were not screened. Family members and their contact information were identified using the patient records. They were then contacted by phone for study information by the first author. Family members who were interested to participate received a postal questionnaire to complete at home.

The questionnaire
Data were collected through a questionnaire that contained questions about the family members’ demographic characteristics, the CA, and professional support from the healthcare services (for example, psychologist, counsellor, and/or psychiatrist). The questionnaire also contained self-reported instruments to measure symptoms of prolonged grief, anxiety, depression, posttraumatic stress, and perceived social support. Each instrument was followed by an open-ended question, for example: ‘If you have any reflections or comments about this part of the survey that concerns grief, you are welcome to write them here.’ An overview of the included instruments is presented in Table 1.

Prolonged grief Disorder-13 (PG-13)
The PG-13 was used to measure symptoms of prolonged grief. The instrument consists of 13 items, of which two are not used to calculate the total score. The remaining items cover cognitive, behavioural, and emotional symptoms. All items have a five-point response format, ranging from ‘Not at all’ (1) to ‘Overwhelmingly’ (5) or from ‘Not at all’ (1) to ‘Several times a day’ (5). The total score is calculated by summing the responses, and the possible score range is 11 to 55; higher score indicates more symptoms of prolonged grief. A cut-off score of ≥ 35 has been suggested. The PG-13 has shown satisfactory reliability and validity.

Hospital anxiety and depression scale (HADS)
The HADS was used to measure symptoms of anxiety and depression. The HADS consists of 14 items divided into two subscales: symptoms of anxiety (seven items) and symptoms of depression (seven items). Each item has a four-point response format ranging from 0 to 3. The subscale scores are calculated by summing the item responses and the possible score range is 0 to 21; higher scores indicating higher symptom levels. The proposed cut-off scores are as follows: normal range (0–7), suggested presence (8–10), and probable presence (11–21). The HADS has shown good reliability and validity.

PTSD Checklist for DSM-5 (PCL-5)
The PCL-5 was used to measure symptoms of posttraumatic stress. The PCL-5 consists of 20 items with a response format that ranges from ‘Not at all’ (0) to ‘Extremely’ (4). The total scale score is calculated by summing the item responses, and the possible range is 0 to 80. Higher scores indicate higher symptom levels of posttraumatic stress, and a cut-off score of ≥ 38 has been suggested. The PLC-5 has shown good reliability and validity.

The Multidimensional scale of perceived social support (MSPSS)
The MSPSS was used to measure perceived social support. The instrument consists of 12 items that cover support from family (4 items), friends (4 items), and significant others (4 items). All items have a seven-point response format ranging from ‘Very strongly disagree’ (1) to ‘Very strongly agree’ (7). A total score can be calculated by summing the item responses and dividing the sum by the number of items. Thus, the possible score range is between 1 and 7, and higher scores indicate higher levels of perceived social support. Three subscales (family, friends, and significant others) can also be calculated by applying the same scoring. No cut-off scores have been identified.

An overview of the included instruments is presented in Table 1.

| Instrument                          | Description                                                                 |
|-------------------------------------|-----------------------------------------------------------------------------|
| Prolonged grief Disorder-13 (PG-13) | Used to measure symptoms of prolonged grief.                                |
| Hospital anxiety and depression scale (HADS) | Used to measure symptoms of anxiety and depression.                           |
| PTSD Checklist for DSM-5 (PCL-5)     | Used to measure symptoms of posttraumatic stress.                            |
| The Multidimensional scale of perceived social support (MSPSS) | Used to measure perceived social support.                                   |
been suggested. The MSPSS has shown good reliability and validity.\textsuperscript{17,21}

\textbf{Statistical analysis}

Missing data not exceeding 25\% per scale were replaced using the persons mean score. In total, seven values from seven different participants were replaced. Descriptive statistics were used to present family members’ characteristics. Continuous data are presented as means and standard deviations, ordered categorical data with medians and quartiles, and non-ordered categorical data with frequencies. Wilcoxon rank-sum test was used to compare differences in symptoms of prolonged grief, anxiety, depression, and posttraumatic stress between family members who was present during the resuscitation and those who were not.

The McNemar test was used to investigate changes in the cut-off scores between the 6 and 12-month assessments while the Wilcoxon signed-rank test was used to investigate changes in the scale scores. The effect size for the Wilcoxon signed-rank test was calculated using Cohen’s \( r \) (small = 0.02–0.30, medium = 0.30–0.50, and large > 0.50).\textsuperscript{32} In addition, to illustrate the number of family members who changed in the outcome measures (PG-13, HADS and PCL-5) between the two assessments, change scores were calculated by subtracting the 12-month assessment from the 6-month assessment; negative change scores reflects decreased symptom levels and positive change scores increased symptom levels.

Simple linear regression analysis was used to explore the associations between the exploratory variables (professional and social support) from the 6-month assessment and the outcome measures (PG-13, HADS, and PCL-5) at the 12-month assessment. To predict the change between the 6 and 12-month assessment, residualized scores were used as outcome variables. This procedure is commonly recommended to measure change using linear regression analysis and implies that the regression is conducted in two steps. First, the 12-month assessment of the outcome variable is regressed on the explanatory variable in a simple linear regression.\textsuperscript{33} Nonparametric bootstrapped confidence intervals and \( p \)-values, based on 2000 replications, was calculated for all regression analyses.

The level of significance was set at \( p < 0.05 \). The regression analyses were performed using the R 4.2.1 (R Foundation for Statistical Computing, Vienna, Austria), including the boot.pval 0.4, sjmisc 2.8.9, and summarytools 1.0.1 packages.

\textbf{Qualitative analysis}

To enhance the understanding of grief reactions as well as professional and social support, the responses to the open-ended questions were analysed using a qualitative content analysis.\textsuperscript{34} The analysis was conducted through searching for descriptions and explanations that could complement, illustrate, and further explain the answers that participants had reported in the instruments in the questionnaire. The comments from the open-ended questions were read through several times and then compiled and organized as grief reactions in relation to professional support and social support. Further, the results of the analysis were discussed in steps by the authors to reach consensus and to agree upon the presentation. In total, 49 participants had written 129 comments. The comments varied from a few words to full pages about thoughts and emotions.

\textbf{Results}

\textbf{Participants flow and characteristics of participants}

During the study period 166 CA events were identified. Of 283 identified family members, 179 were contacted for information and inclusion. In total, 108 questionnaires were returned for the 6-month assessment. The follow-up assessment for the present study was conducted 12 months after the death and was completed by 69 family members (Fig. 1). No significant differences were shown between the participants and dropouts regarding sex, age, prolonged grief, anxiety, depression, or posttraumatic stress.

The participants in the present study were family members of 52 deceased persons 60–91 years old, of whom 56 \% (n = 29) were men. The median age of the participants was 62 years (IQR = 52–71), a majority were women (n = 46, 67 \%). About one third of the participants (n = 26, 38 \%) had been present during the resuscitation attempts and they reported significantly higher symptom levels of prolonged grief 6 months after the death (\( z = -2.53, p = 0.011 \)) and higher symptom levels of posttraumatic stress at both 6 and 12 months after the death (\( z = -2.65, p = 0.008 \) and \( z = -2.16, p = 0.031 \)) compared to those who was not present. More details about the participants are presented in Table 2.

\begin{table}[h]
\centering
\caption{Overview of self-reported instruments.}
\begin{tabular}{|c|c|c|c|c|c|}
\hline
Instruments & Constructs & Items & Scales & Score range & Cronbach’s \( \alpha \) \textsuperscript{a} \\
\hline
PG-13 & Prolonged grief & 13 & One total scale & 11–55 & 0.93 (0.90, 0.95) \\
HADS & Anxiety and depression & 14 & Two subscales (anxiety and depression) & 0–21 & 0.90 (0.86, 0.93) \\
PCL-5 & Posttraumatic stress & 20 & One total scale & 0–80 & 0.89 (0.84, 0.92) \\
MSPSS & Perceived social support & 12 & One total scale and three subscales (family, friend, and significant others) & 1–7 & 0.94 (0.92, 0.96) \\
\hline
\end{tabular}
\end{table}

\textsuperscript{a} Cronbach’s alpha values in the present study including the 95\% confidence interval within brackets.
Variations in symptoms of prolonged grief, anxiety, depression, and posttraumatic stress

Analyses of the cut-off scores at the 6-month assessment showed that symptom of anxiety was most common (n = 22, 32 %) followed by prolonged grief (n = 10, 14 %) and depression (n = 10, 14 %) and finally posttraumatic stress (n = 3, 4 %). At the 12-month assessment, the same pattern was seen, but prolonged grief was now more common than depression (17 % and 9 %, respectively). Based on these cut-off scores, no significant changes were shown from the 6-month assessment to the 12-month assessment (Table 3).

Analyses of the scale scores showed a significant decrease in symptoms of prolonged grief (p = 0.017) and anxiety (p = 0.021) between the two assessments but the effect size was small, 0.29 and 0.28 respectively. No significant change was seen for symptoms of depression and posttraumatic stress (Table 3).

According to the change scores, most bereaved family members improved or did not change in symptoms of prolonged grief, anxiety, depression, and posttraumatic stress between the 6 and 12-month assessment. However, a substantial share reported higher symptom levels at the 12-month assessment compared to the 6-month assessment (Fig. 2). Increased symptom levels were most common for posttraumatic stress (n = 25, 36 %) followed by prolonged grief (n = 23, 33 %), depression (n = 22, 32 %), and anxiety (n = 17, 25 %).

Grief reactions in relation to professional support

Professional support at the 6-month assessment was significantly associated with symptoms of prolonged grief, anxiety, depression, and posttraumatic stress at the 12-month assessment. Hence, having professional support implied higher symptom levels. Based on the residualized scores, professional support could not predict the change in any of the outcome variables (Table 4).

The family members described how they wanted a peaceful environment and professionals who stayed close and were available for questions and conversations. A daughter commented: “We were treated wonderfully by the emergency room support staff who were nearby throughout our stay there.”

Many pondered if they could have acted differently before and during the CA and wrote about self-blame. Follow-up conversations with professionals reduced questions. A daughter commented: “I’m glad we were told by a doctor, via a later call, about how a sudden
cardiac arrest happens. /.../ It helped me even though it was a shock when we got the phone call.”

A widow commented the delivering of the death notification by phone: “It was a shock. We weren’t prepared for it, neither me nor my children. I’ve received no support at all from the department [at the hospital] where my husband died. I’ve had to find a doctor and a psychologist myself.”

Family members wrote about their need for professional support, but lack of time and energy hindered them from seeking the support, and some also had worries about not being able to afford it. A widower wrote about the disappointing lack of support from the health care services, and instead he received social support from colleagues.

Grief reactions in relation to social support
All sources of social support from the 6-month assessment were significantly associated with symptoms of depression and posttraumatic stress at the 12-month assessment. However, no source of social support from the 6-month assessment was significantly associated with prolonged grief at the 12-month assessment, and only social support from friends was significantly associated with symptoms of anxiety. Based on the residualized scores, social support could not predict the change in any of the outcome variables (Table 4).

The comments revealed that family members often had lost an important part of their social support, the part the deceased person used to provide. A widower commented that the close relation to his family could not ease his longing for his wife. Despite having close relations, some family members wrote about holding back their own grief reactions. One family member commented: “I struggle with my grief among others. I don’t want to be a burden.” Family members also worried about other persons’ grief reactions and need of support. A daughter commented: “The hardest part when my mom died was taking care of my dad. I didn’t have time to grieve, but now I feel better.” However, family members also wrote about how they

| Table 2 – Characteristics of participants (n = 69). |
|-----------------------------------------------|
| Age, Mdn (IQR) | 62 (52–71) |
| Sex, n (%) |
| Woman | 46 (67) |
| Men | 23 (33) |
| Country of birth, n (%) |
| Sweden | 67 (97) |
| Other Nordic country | 2 (3) |
| Marital status, n (%) |
| Widow/widower | 27 (39) |
| Married/registered partner | 25 (36) |
| Unmarried | 11 (16) |
| Divorced | 6 (9) |
| Cohabiting, n (%) |
| Living alone | 33 (48) |
| Living with someone else | 36 (52) |
| Occupation, n (%) |
| Employed | 29 (42) |
| Unemployed | 1 (1) |
| Retired | 34 (49) |
| Sick leave | 4 (6) |
| Student | 1 (1) |
| Highest education, n (%) |
| Primary school | 17 (25) |
| High school | 26 (39) |
| University | 24 (36) |
| Missing data | 2 |
| Relation to the deceased, n (%) |
| Spouse | 25 (38) |
| Adult child | 36 (52) |
| Parent | 1 (1) |
| Sibling | 3 (4) |
| Father-in-law | 1 (1) |
| Daughter-in-law | 1 (1) |
| Nephews | 1 (1) |
| Friend | 1 (1) |
| Been present during resuscitation attempts, n (%) | 26 (38) |
| Professional support, n (%) | 20 (29) |
| Social support 6 months post death, Mdn (IQR) |
| MSPSS total scale | 6.4 (5.4–6.9) |
| Family | 6.8 (5.5–7.0) |
| Friends | 6.0 (5.0–7.0) |
| Significant others | 6.8 (5.5–7.0) |

MSPSS = Multidimensional Scale of Perceived Social Support.
engaged in new activities and relationships and thus tried to strengthen their social network. A family member commented that sharing experiences with other bereaved persons in a support group had helped her in her grief process.

Table 3 – Symptoms of prolonged grief, posttraumatic stress, anxiety, and depression 6 and 12 months after death (n = 69).

|                        | 6-month assessment | 12-month assessment | p-value | Effect size c |
|------------------------|--------------------|---------------------|---------|---------------|
| Symptoms of prolonged grief (PG-13), Mdn (IQR) | 22 (16–32) | 21 (16–28) | 0.013 a | 0.29 |
| No cases (11–34), n (%) | 59 (86) | 57 (83) | 0.724 a |
| Cases (35–55), n (%) | 10 (14) | 12 (17) | |
| Symptoms of anxiety, (HADS), Mdn (IQR) | 5 (2–9) | 4 (1–8) | 0.016 a | 0.28 |
| Normal range (0–7), n (%) | 47 (68) | 51 (74) | 0.387 a |
| Suggested or probable presence (8–21), n (%) | 22 (32) | 18 (26) | |
| Symptoms of depression, (HADS), Mdn (IQR) | 2 (1–6) | 2 (1–4) | 0.142 a | 0.17 |
| Normal range (0–7), n (%) | 59 (86) | 63 (91) | 0.206 a |
| Suggested or probable presence (8–21), n (%) | 10 (14) | 6 (9) | |
| Symptoms of posttraumatic stress (PCL-5), Mdn (IQR) | 7 (2–19) | 8 (2–16) | 0.677 a | 0.07 |
| No cases (0–37), n (%) | 66 (96) | 68 (99) | 0.480 a |
| Cases (38–80), n (%) | 3 (4) | 1 (1) | |

PG-13 = Prolonged Grief Disorder-13, HADS = Hospital Anxiety and Depression Scale, PCL-5 = PTSD Checklist for DSM-5.

a Wilcoxon signed-rank test with continuity correction.

b McNemar test with continuity correction.

c Cohen’s r (small = 0.02–0.30, medium = 0.30–0.50, large > 0.50).

Fig. 2 – The graph illustrates the distribution of change scores between the 6-month assessment and the 12-month assessment for Prolonged Grief Disorder-13 (PG-13), Hospital Anxiety and Depression Scale (HADS), and PTSD Checklist for DSM-5 (PCL-5). Zero values imply unchanged symptom levels while negative change scores reflect decreased symptom levels and positive values reflect higher symptom levels at the 12-month assessment compared to the 6-month assessment.
To the best of our knowledge, this is one of the first studies that has considered the importance of professional support including contact information. Even though a proactive approach, for example providing follow-up measures with a support person present during resuscitation, can be beneficial for both family members and staff as it may reduce symptoms of psychological distress among family members. For example, having a support person present during resuscitation can decrease symptoms of prolonged grief, anxiety, depression, and/or posttraumatic stress. Nevertheless, family presence has been shown to reduce symptoms of prolonged grief, anxiety, depression, and posttraumatic stress at the 12-month assessment. Therefore, family presence during resuscitation should be considered to improve the health and well-being of family members and staff. However, the support must match the perceived social support to be effective. Furthermore, social support may strengthen the ability of family members to cope. However, distressed persons who lack the ability to cope might not be able to request support, and over time drive away potential support. Peer-support may strengthen the ability of family members to cope. However, distressed persons who lack the ability to cope might not be able to request support, and over time drive away potential support. Peer-support may strengthen the ability of family members to cope. However, distressed persons who lack the ability to cope might not be able to request support, and over time drive away potential support. Peer-support may strengthen the ability of family members to cope. However, distressed persons who lack the ability to cope might not be able to request support, and over time drive away potential support. Peer-support may strengthen the ability of family members to cope. However, distressed persons who lack the ability to cope might not be able to request support, and over time drive away potential support. Peer-support may strengthen the ability of family members to cope. However, distressed persons who lack the ability to cope might not be able to request support, and over time drive away potential support. Peer-support may strengthen the ability of family members to cope. However, distressed persons who lack the ability to cope might not be able to request support, and over time drive away potential support. Peer-support may strengthen the ability of family members to cope. However, distressed persons who lack the ability to cope might not be able to request support, and over time drive away potential support.
associated with symptoms of anxiety.\textsuperscript{10,44} In the present study, no differences in anxiety were shown. Instead, family presence was associated with higher symptom levels of prolonged grief and post-traumatic stress. It is likely that family presence is of different meanings for different persons and that other factors such as the relation to the deceased person are of greater importance. This explanation is supported by the family members’ comments showing that both being present and not being present at the time of death caused challenges in the grief process. Thus, family members’ individual grief reactions and the ability for coping with bereavement require different kinds of proactive interventions of support after deaths from sudden cardiac arrests.

**Limitations**

This study had a limited sample size and hence the results should be generalized with caution. Problems with recruiting participants and high rates of dropouts are common in bereavement research.\textsuperscript{38,45,46} However, the dropout analysis showed no significant differences between participants and non-participants. No reminders were sent out of ethical considerations for bereaved family members’ vulnerable situation. To strengthen the validity, the representative quotations were derived from different participants and will help readers to assess the authenticity and trustworthiness of the results.

**Conclusion**

The high symptom levels of grief reactions among family members indicate a need for both professional and social support. Thus, the results point to the importance of proactive and available support over time to meet family members’ various needs.

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**CRediT authorship contribution statement**

Nina Carlsson: Conceptualization, Methodology, Data curation, Formal analysis, Writing – original draft. Annette Alvariza: Supervision, Conceptualization, Methodology, Writing – review & editing. Lena Axelsson: Supervision, Conceptualization. Anders Bremer: Supervision, Conceptualization. Kristofer Arestedt: Supervision, Conceptualization, Methodology, Data curation, Formal analysis, Writing – review & editing.

**Author details**

\textsuperscript{a}Faculty of Health and Life Sciences, Linnaeus University, Kalmar/ Växjö, Sweden \textsuperscript{b}Department of Health Care Sciences/Palliative Research Centre, Marie Cederströld University, Stockholm, Sweden \textsuperscript{c}Capio, Palliative Care, Dalen Hospital, Stockholm, Sweden \textsuperscript{d}Sophiahemmet University, Stockholm, Sweden \textsuperscript{e}Department of Ambulance Service, Region Kalmar County, Kalmar, Sweden \textsuperscript{f}Department of Research, Region Kalmar County, Kalmar, Sweden

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