How to Care for the Brought in Dead and their Relatives. A Qualitative Study Protocol based on Interpretive Description

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Title Page

Title: How to Care for the Brought in Dead and their Relatives. A Qualitative Study Protocol based on Interpretive Description.

Running Title: How to Care for the Brought in Dead and their Relatives in an Emergency Department. A Protocol for a Qualitative study within the Methodology Interpretive Description.

Keywords: Applied Research, Emergency Care, Interpretive Description, Nursing, Palliative Care, Prolonged Grief Disorder, Qualitative Methods, Qualitative research, Research Protocols.

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Authorship
All authors meet the ICMJE recommended criteria. All authors have made substantial contributions to the design of this manuscript. DGB has drafted the manuscript and all of the other authors have substantively revised it.

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Conflict of interest
The authors have no conflict of interest to declare.
ABSTRACT

Aim: This project has two aims: 1) What do relatives to brought in dead describe as helpful and supportive care when they arrive at the emergency department to see and say goodbye to a deceased? 2) What do nurses describe as good nursing practice for brought in dead persons and their relatives and what may hinder or facilitate this practice in an emergency setting?

Design: A qualitative study within the methodology Interpretive Description.

Methods: Data will be collected through three data sources: Individual interviews with relatives to brought in dead persons, participant observations of relatives to brought in dead persons during their presence in the emergency department and focus group interviews with emergency nurses.

Discussion: Brought in dead persons and their relatives are received and cared for in emergency departments by emergency nurses. Knowledge of how to render care for the relatives to brought in dead persons in an acute setting including what skills and competences this require of the nurses is warranted. We need to explore, describe and comprehend the experiences of both the relatives and the nurses in order to point out potential areas of improvement.

Impact: This paper is a protocol of an Interpretive Description study offering insight into considerations and reflections in designing the study.

Keywords: bereavement, death, emergency department, family care, interpretive description, nursing, palliative care, qualitative research, research design, sudden death
INTRODUCTION

Persons who have died unexpectedly at home, in the street, at work, in traffic or on the way to the hospital are globally received and cared for in Emergency Departments (ED). This group of persons are labelled “brought in dead” (BID) or “dead on arrival” (DOA). When a BID person arrives at the ED they are either transferred to a remote room or to the chapel nearby where they stay until they are transferred to another hospital or institute for autopsy, released for funeral or a similar arrangement.

Common for all BID persons and their relatives are that death has occurred unexpectedly and unplanned. The loss of a loved one is a painful and stressful event, though most individuals have sufficient internal resources and external support to cope with their grief and slowly adjust to life without the deceased. However, situational factors such as place of death, lack of preparation for the loss and traumatic death is associated with an increased risk of prolonged grief disorder (PGD) (Prigerson et al. 2009, Mancini et al. 2015). PGD is besides, intense emotional pain and reduced quality of life, associated with increased risk of morbidity and mortality (Prigerson et al. 2009, Mancini et al. 2015). The prevalence of PGD among relatives is 9.8 % for non-traumatic deaths increasing to 13-71 % for traumatic death (M. S. Stroebe et al. 2006, M. Stroebe et al. 2007, Lundorff et al. 2017).

BACKGROUND

EDs are designed to save patients’ lives, as well as maintaining a high patient flow thus knowledge about palliative care is not in demand or valued (Chan 2004, Beckstrand et al. 2012, Fernandez-Sola et al. 2017). However, at the same time emergency nurses (ED-nurses) are expected to care for BID persons and their relatives.

After death care includes making the deceased look presentable to the relatives, as well as nurses being present and caring for the relatives while they are with the deceased (Olausson & Ferrell 2013a, Olausson & Ferrell 2013b). Caring for BID persons and their relatives require the ED-nurses to leave the ED for an unknown period and hand over the responsibility of other patients and tasks to nurse colleagues.

Leaving the ED to care for BID persons and their relatives means a shift in context and a shift in nursing focus from “doing to being”. In “doing” the focus is on saving lives, the tasks are practical oriented in a work environment marked by rapid decisions making, action and a high patient flow. “Being” as in being present and available require nurses to be non-
instrumental, sensitive, provide emotional support and be able to create room for the relatives to grief.

The ED-nurses in the clinic studied here find this shift of context and focus difficult and describe caring for BID persons and their relatives as stressful and demanding as well as being a complex nursing task. The frequency and number of BID persons received in the ED and need for subsequent care for their relatives constitute a significant practical problem for the ED-nurses. According to existing research lack of knowledge, lack of time and dedication increases the risk of professional stress and burnout among nurses (Maslach & Leiter 2008, Parola et al. 2017, Durand et al. 2019).

Care for relatives is described as an integrated part of palliative care but often in a context where patient, relatives and healthcare professionals have established a relationship prior to death (The World Health Organization 2015, Sundhedsstyrelsen [Danish Health Authority] 2017). Palliative care for relatives and the BID persons are likely to obtain limited focus and low priority in the ED as the overarching goal in the ED is to save lives and maintain a high patient flow, consequently nurses and physicians are trained and acknowledged for their instrumental life-saving skills (Beckstrand et al. 2012, Decker et al. 2015, Hogan et al. 2016, European Society For Emergency Medicine (EUSEM) 2017, Sundhedsstyrelsen [Danish Health Authority] 2017, Diaz-Cortes et al. 2018, Berbis-Morello et al. 2018). However, caring for BID persons and their relatives require different skills and competencies and must be rendered.

In scaffolding this study, we reviewed the literature and conducted several literature searches in both research databases, webpages and local archives with the overall aim to identify knowledge about both BID persons and BID relatives. In collaboration with an experienced research librarian, we conducted a systematic literature search in the scientific research databases: Medline, PsychINFO, and Cinahl. We identified only sparse relevant literature about BID persons and their relatives (Chiang & Wang 1999, Kent & McDowell 2004, Scott 2013, Khursheed et al. 2015, Naneix et al. 2015, Mowll et al. 2016), and none offered guidance of how to care for the adult BID relatives in an acute care setting.

The relatives of BID persons are a special and vulnerable population, and existing knowledge on how to provide aftercare for relatives of persons with malign or non-malign palliative needs cannot simply be generalized to the BID population as the situation of death and context for care differ significantly. We do not question that caring for BID persons and their relatives
relatives should be the responsibility of nurses, as it in every way draws on the core competencies of nursing. However, knowledge on how to support the grieving process of BID relatives in an ED context and what skills and competencies this require of ED-nurses is warranted. In order to point to potential areas for improvement, we need to explore, describe and understand the experiences of both the BID relatives and the ED-nurses. This will enlighten us and facilitate designing and developing directions for appropriate care for BID persons and their relatives and may thereby contribute to relieve both emotional pain and reduce the risk of PGD among BID relatives and secondly prevent work-related stress among ED-nurses.

AIM AND RESEARCH QUESTIONS

The overall aim of this project is to improve care for BID persons and their relatives in the ED. In order to develop and improve practice it is of central importance to include and explore the perspectives of those involved, in this project the relatives of BID persons and the ED-nurses.

The research questions guiding this project are:

1. What do BID relatives describe as helpful and supportive care when they attend the ED to see and say goodbye to the deceased?
2. What do ED-nurses describe as good nursing practice for BID persons and their relatives and what may hinder or facilitate this practice in an ED setting?

METHODS

Design

This is an explorative project, investigating the perspectives of the two main groups involved in caring for BID persons and their relatives (BID relatives and nurses). The project is based on the qualitative inductive methodological approach of Interpretive Description (ID) as described by Sally Thorne (Thorne S. 2016). ID is chosen as a research strategy as ID is an applied approach occupied with solving disciplinary questions by seeking out the kind of knowledge needed to inform and potentially change practice in a credible and defensible way building on existing empirical evidence (Hunt 2009, Thorne S. 2016). Our project originates from clinical problems faced by ED-nurses every day and we find that the epistemology of ID is consistent with the knowledge required to answer our research questions. This also includes offering the flexibility of “borrowing” from other research strategies if it is
appropriate and inform the research process in a way that enhances credibility (Thorne et al. 1997, Thorne S. 2016).

**Types of data**

Data will be constructed through three data sources: Individual interviews with BID relatives, participant observations of the BID relatives during their visit to the ED and focus groups with healthcare professionals. We use multiple data sources to explore the different perspectives and perceive it as a way to increase credibility and reduce the risk of falling into the epistemological traps that each data source might present (Thorne S. 2016).

We are interested in data that provides us with insight and knowledge about the interactions between BID relatives and ED-nurses, the relatives’ experiences attending the ED, the healthcare professionals’ experiences with BID care and the interactions, culture and perspectives of ED-nurses and other health professionals in relation to BID persons and their relatives (Bourgeault et al. 2013). In-depth, nuanced and rich data is not something immediately available and collectible for the researcher entering the field. Therefore, in accordance with Thorne, we use the word “constructing data” to draw attention to the active role of the researcher and her impact on data in the sense of the questions she asks, what she observes, and how she interacts with the study participants (Thorne S. 2016).

The interviews and focus groups will generate data through linguistic interpretation and reflection and help investigate subjective experiences and perspectives (Crabtree BJ & Miller WL 1999). Participants observations provide data and insight into behaviours and context (Spradley JP 1980), and will contribute to nuance the individual interviews and focus groups as consistency between what is said and what is done, do not always exist. We expect that the chosen methods and data triangulation can help us see beyond a single angle of vision and extend the range of insight and knowledge produced as well as enhancing the quality of the research (Thorne S. 2016, Flick U. 2018).

**Setting**

All study participants will be recruited from the ED at North Zealand Hospital, a hospital located in the Capital Region of Denmark. The ED is a medium size Danish ED employing approximately 100 ED-nurses and treating in average 300 patients per day and 350 BID persons per year. In average, one dead Danish person leaves four relatives, corresponding to 1400 relatives per year in our setting (Det nationale sorgcenter [The Danish National Center for Grief] 2018).
Study participants

Study participants will be BID relatives, healthcare professionals and other collaborators. We are looking for patterns and variations and it is therefore impossible to describe a pre-study fixed sample size; however, we have estimated a minimum of study participants to be able to understand and describe the complexity in our research questions. The BID populations and their relatives are highly heterogenic why the sampling strategy for both interviews and observations will be aimed at both typical, unique, extreme and deviant cases. We will attempt to achieve maximum variation in cause of death, age, gender, family relationship and ethnicity. However, ethical considerations will inevitably affect our sampling and we will at all interactions be sensitive to how disturbing study participation might be for the relatives (Crabtree BJ & Miller WL 1999, Thorne S. 2016).

For the interviews and observations, we consider 20 interviews with BID relatives, 50 hours of observation and two focus groups as a minimum. We have no upper limit for inclusion, but a timeframe of one year that may affect the sample size and force us to terminate or restrict the numbers of further study participants (Thorne 2020).

Inclusion criteria

Study participants for individual interviews (BID relatives): Adult relatives of BID persons who attend the ED and who are willing to participate in interviews, Danish speaking and able to provide informed consent.

Study participants for observation (Situations and events): Situations where the BID relatives attend the ED to see and say good bye to a deceased will be relevant for observation.

Study participants for focus groups (ED-nurses and other healthcare professionals): ED-nurses employed at the ED for a minimum of one year and who have cared for at least five BID persons and their relatives will be eligible. If the first focus groups show that the perspectives of physicians, paramedics, police, chapels porters and/or ambulance officers may contribute important data and perspectives another focus group will be conducted.

Exclusion Criteria

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Relatives who are unwilling to participate or are unable to provide informed consent or assessed by the ED nurses as “not appropriate for inclusion” will be excluded. If it is assessed by an ED-nurse that the relative need to be excluded for ethical reasons this will be respected.

Recruitment

Eligible relatives for individual interviews will be identified and approached by the ED-nurses when they attend the ED to see the deceased. Information and possible recruitment will take place after the relatives have said goodbye to the deceased and prior to their departure from the ED. The ED nurses will briefly inform the relatives about the research project and will after their oral consent hand over written information about the research project. The relatives will be asked for permission for the research team to contact them by telephone after approximately 14-21 days to provide information of the project in detail and to include them as participants if found relevant and they agree. The purpose of the delay in time before the contact, is to give the relatives time to consider their participation and time to tend to necessary practical tasks like funeral, finances etc.

Situations relevant for observation will be identified by the ED-nurses and they will contact the researcher (DGB). As BID persons come unplanned, some of the observations will be selected randomly or by convenience as participant observation requires that the researcher is present and available at the actual time. Relatives access to the deceased will never be delayed or restricted in order to fit into the schedule of the researchers. It will always be the researcher who must adapt to the relatives’ plan and needs.

Healthcare professionals eligible for participation will be approached directly by the research team. The healthcare professionals will be informed both orally and in writing about the project and asked for oral and written consent before participating a focus group. In all cases, it is the researcher (DGB) who is responsible for obtaining informed consent prior to any activity.

Data collection

The interviews and focus groups generate data through communication and help to explore subjective experiences and perspectives. Participants observations provide data and insight into behaviours and context. The data collection and analysis will be conducted in an iterative process, and data will be collected through all sources in a parallel process as each data collection event build on insight gained from the previous observations, interviews or focus groups.
Participant observations

Permission to do participant observation has been obtained from the ED management and the head nurse. The observer (DGB) is an experienced nurse and researcher and will in collaboration with the ED-nurses be present and take part in caring for the relatives in the observed situations. The observer will present herself to the relatives as a nurse and researcher and inform that she will be present and accompanying the ED-nurses with the purpose of assisting them and at the same time observing and learning about what goes on in the specific situation (Spradley JP 1980, Creswell JW 2013). By presenting herself as both a researcher and nurse, the relatives are given the opportunity to oppose to the observer (DGB) being present or they may ask elaborate questions.

The observations provide a platform from which to reflect upon behavior and context as it plays out in its natural surroundings (Crabtree BJ & Miller WL 1999, Thorne S. 2016). The observations are planned as participant observations and has two purposes: (1) to engage in activities appropriate for the situation; and (2) to observe the activities and interaction between the BID persons, BID relatives and ED-nurses. Although the observer is a nurse, she is not a part of the ED-nurse group and their daily practice and therefore not, prior to the study, socialized into the ED nurses’ logic and perspectives (Spradley JP 1980, Thorne S. 2016).

The observations will be guided by Spradley’s recommendation for conducting participant observations (Spradley JP 1980), where descriptive, structural and contrast questions will be applied throughout the simultaneously ongoing process of moving from descriptive “grand-tour” observations to descriptive “Mini-tour” observations, towards “selective-“ and eventually “focused observations”. “Grand-tour” descriptive observations will be aimed at gaining an overview of the situation and interaction between the BID persons, relatives and ED-nurses. Whereas “Mini-tour” observations will focus on a more in-depth investigation of aspects of the observed situation and interaction identified based on previous data and findings, such as space, actors, activity, object, act, event, time, goal and feeling. Moving from descriptive observations, where we try to describe what is going on (happening) as broadly as possible, “focused observations” will enable us to begin tuning in to specific discoveries before we in “selective observations”, with increasingly refinement, will focus on...
selected meanings in the observed situations and interactions, but also deselect less
significant observations. The researcher (DGB) will take condensed “naive” field notes,
during and immediately after the observations, completing and expanding them by typing
them verbatim at the earliest opportunity. The field notes will continuously be discussed with
members of the research team (Spradley JP 1980).

**Individual Interviews**

The interviews will be conducted by DGB face to face, and in a place of the relatives’ choice.
The duration of each interview is estimated to last 30-45 minutes. The interviews will be
based on a semi-structured interview topic guide (Figure 1) and audio recorded. The topics
are based on the research teams’ empirical experiences and existing literature. The interview
guide covers the main topic of the project, providing a structure for the discussion during the
interviews, and at the same time giving the researcher the opportunity to pursue interesting
statements. The interview guide may be altered and focused as our knowledge and insight
increases during the data collection period. The main focus is on providing a safe atmosphere
that encourages the relatives to share their perceptions and experiences, although those
experiences and feelings may not be positive or pleasant (Thorne S. 2016).

**Focus Group Interviews**

We plan to conduct two focus groups with eight to ten participants in each group. The focus
groups will be conducted in a meeting room, outside the ED, but located at the hospital. This
location is chosen because it is convenient for the participants and there will be no
disturbance from the ED. The day and time for the focus groups will be scheduled and agreed
with the head nurse of the emergency department several weeks in advance to prevent stress
and hassle among the participants. Snacks and beverages will be served during the focus
groups as eating together tends to promote conversations and communication within a group
(Krueger & Casey 2000).

The focus groups will be led by a moderator (DGB) and co-moderator with the aim to
facilitate a synergetic discussion about shared beliefs, perceptions and attitudes within the
group of ED-nurses and at the same time enlighten multiple perspectives and diverse
experiences. The moderator will during the first few moments of the focus group describe
how there is no right or wrong answers and that we expect and appreciate different points of

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views. The moderators will guide the discussion in the focus group based on a broad not static topic guide (Figure 2) based on existing knowledge and the understanding and insight accommodated through the observations and interviews already conducted (Crabtree BJ & Miller WL 1999, Webb & Kevern 2001, Krueger & Casey 2009). We will make reflective notes immediately after the interviews/focus groups and transcribe the interviews verbatim within a week.

ETHICS

The topic of this research project is sensitive and demand careful ethical considerations to safeguard the wellbeing of participants throughout the project. The project includes relatives of persons who have died unexpectedly, and the relatives will naturally be affected by acute grief and sadness. All interviews and observations will be conducted by a senior researcher (DGB) with considerable experience, both as a researcher and clinically as a nurse, in end-of-life care and in supporting bereaved.

All participation in this project is well informed and voluntarily. Previous studies related to death, organ donation, and bereavement have illustrated that it do not constitute a problem to talk with bereaved relatives if this is done within a clear framework, by an experienced person and with sensitivity and respect (M. Stroebe et al. 2003, Gysels et al. 2012, Bremer et al. 2012, Sque et al. 2014, Kentish-Barnes et al. 2015, Laurent et al. 2019). If it comes to our notice during interviews that the relatives, or nurses express signs of distress the interview will be stopped or paused. The participants will be asked if they, after having a break, would like to continue the interview or if they prefer to discontinue. If the participants want to continue the interview will resume, otherwise it will be ended. If there is a need of additional professional help, the researcher will encourage or help the study participants to seek the relevant support or point them in a relevant direction to do so. Psychological assistance or debriefing can be required for both relatives, nurses or researchers if needed (Sque et al. 2014, Noyes et al. 2017).

All data are anonymized and carefully stored in a secured place approved by the Danish Data Protection Agency (VD-20019-03) and in accordance with the General Data Protection Regulation (GDPR). All field notes and transcriptions are erased for names and other potentially identifiable materials. In situations with deviant or extreme cases, we will be especially aware of safeguarding data and the study participants making identification of study participants impossible.

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According to the Ethics Committee (www.nvk.dk) in Denmark, the Biomedical Research Ethics Committee System Act does not apply to this type of project or to qualitative studies in general. This project is designed and will be carried out in accordance with the guidelines of the declaration of Helsinki (World Medical Association 2013). The project governance is conducted by an interdisciplinary group of leaders, researchers and clinicians, all with experiences within palliative care and bereavement. All ethical aspects and how to mitigate harm to both participants and researchers are continuously discussed in this group.

RIGOUR

In qualitative research different methodological traditions have somewhat distinct guidelines and standards by which they recommend that credibility is evaluated (Crabtree BJ & Miller WL 1999, Malterud 2001, Tong et al. 2007). In a project guided by ID, the following four criteria form the basis for articulation evaluation standards: 1) “Epistemological Integrity”, which means that the project must demonstrate a defensible line from the research questions to the findings. The nature of the knowledge must be consistent with the stated epistemological standpoint; 2) The project must show “Representative Credibility” so that the sampling strategy reflect the phenomenon studied; 3) The reporting of the research process and subsequent findings must reflect a “Analytic Logic” and have a visible audit trail; and 4) The project must reveal “Interpretive Authority”. All knowledge is perspectival and contextual and therefore we need to be assured that the researchers’ interpretation is trustworthy and reveal some truth beyond the researchers’ own bias or experiences (Thorne S. 2016). We have intended to integrate and describe credibility throughout the previous sections in relation to each element of the research process (Thorne S. 2016).

ANALYSIS

The analysis will be conducted concurrently with the data collection and therefore the amount of data will increase consecutively. We expect the total amount of data to be large and to prevent being overwhelmed with volumes of information all data will be anonymized and transferred to the software program QRS NVivo 12 ©. QRS NVivo will be used with caution not to lead to a premature lock on ideas and assumptions (Thorne S. 2016). However, NVivo may help us sort and organize data during the data construction and analysis phases and thereby support the analytic process and enhance transparency.
Data will at first be considered as two units for analysis, one with a BID relatives’ perspective and one with a healthcare perspective. However, if considered appropriate, the two units will be merged into a unified dataset later in the analysis.

The first step in the analysis will be to immerse and familiarize oneself with data and develop a sense of the whole beyond the immediate impression of what data covers. A part of becoming familiar with data as well as allowing oneself to reflect on the initial parts of data, consists of the researcher (DGB) herself conducting the transcriptions (Crabtree BJ & Miller WL 1999, Thorne S. 2016).

The transcriptions will afterwards be grouped and structured into broad generic codes reflecting what the piece of text is about. Next step will be to find ways that the broad codes relate to each other or differ by looking for meaningful patterns and variations. Moving the process of analysis forward from a data near and descriptive state towards a “thematic summery” we begin asking questions like “so what”, “what does this mean” and thereby move the process to a higher level of abstraction. What we are aiming for is gaining knowledge and understanding that goes beyond the self-evident and already known, and knowledge that can guide the future nursing organisation and care for BID relatives by offering solutions. The aim is, that we by the end of the analysis are able to articulate a credible “table of content” presenting the major heading and minor subheadings shaping our finding in the form of thematic statements (Thorne S. 2016).

Our research aims will guide the analysis and keep us focused on the applied approach, but the analysis is an intellectual process and it is not possible to describe exactly how this process is best supported before actually knowing our data. We will keep an analytic journal, writing down our reflection, decisions, discussion etc. throughout the analytic phase (Thorne S. 2016).

The analysis will be carried out in a collaboration between all the members of the research group, where several of the members work in the ED and take part in caring for the ED. Three of the authors (DGB, HT and SFH) will take the lead on the analysis and be the ones who work closest to the original data.

DISCUSSION

In identification of “state of the science” we discovered a knowledge gap about how to care for relatives to adult BID persons. It is our belief that care for BID persons and their relatives is a core nursing task and best handled by nurses. Nurses are aware that support of the
relatives and rituals related to the time after death can help relatives make sense of the chaos and facilitate the grieving process. However, care of BID persons and their relatives differ from other population and palliative care in general as they are handled in an acute setting and by ED-nurses and by the fact that the ED-nurses do not know neither the BID persons and their relatives prior to death nor are familiar with the trajectory that may have led to death (Olausson & Ferrell 2013a, Cooper et al. 2019).

Knowledge of how to organize the care of BID and their relatives including which nursing competencies are required are yet unknown and unexplored and could be useful knowledge to nurse managers in organizing the work and staff in an ED. This project is not initiated with the ambition to provide truth and generalizable knowledge, but rather to generate knowledge and insight that may help us and our nurse colleagues understand what can be done to improve the care of BID persons and their relatives. This paper describes a qualitative research protocol. We hope that, by making our reflections explicit and transparent, this paper will help and inspire other researcher within the applied research practice.

This protocol is not comparable to a quantitative research protocol which is a more static document and something that the researchers can not deviate from (Schulz et al. 2010). Because ID is a “logic model rather than a cookbook” (Thorne S. 2016), a study informed by ID may take many forms leaning on different approaches. This qualitative protocol should be read as a mere description of the considerations and reflections of the research team during scaffolding and framing the project. However, if the assumptions and choices described in the protocol becomes inappropriate or irrelevant during the study, required adjustment will be made and described in a subsequent paper reporting the findings.

Limitations

A potential limitation is that some of the bereaved persons might be so marked be grief that they are unwilling or unable to participate. Care and protection of the relatives will always have the highest priority in this project, although these relatives properly could contribute important knowledge and insight. Social desirability is always a possible bias in interviews. However, in this project we aim to reduce this risk of bias by the data source triangulation.
REFERENCES


Creswell JW (2013) *Qualitative Inquiry and Research Design*. SAGE.


Flick U., ed. (2018) Doing Triangulation and Mixed Methods. SAGE.,


Sundhedsstyrelsen [Danish Health Authority] (2017) Anbefalinger for den palliative indsats [recommendations for palliative care]. (1.0).


### Figure 1. Main topic for the interviews with relatives

**1. Please tell me about the day where you lost your wife, son…**

- What happened?
- What led to his or her death?
- Who told you about the death and how?
- How did you feel when it happened?
- Who took care of you and how?

**2. Please tell me about your attendance at the ED**

- What did you expect would happened in the ED?
- What happened when you arrived at the ED?
- Who and how were you cared for in the ED?
- What did you feel?
- What was your actual need for support?

**3. Please tell me about your experience with seeing and being with our wife, son…**

- What was your first thoughts?
- What was important to you (and others in your family) in the situation?
- What did you think about the room/place where the deceased was lying?
- How did your wife, father, sister, son look?
- How could the nurses support you in the specific situation, what where your needs of care?

**4. What happened then?**

- What were your feelings leaving the ED?
- How did you manage the hours and days after?
- How could the ED nurses support you and help you through this phase, what were your needs?
<table>
<thead>
<tr>
<th>Research topics</th>
<th>Keywords</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organisation and planning of BID care</td>
<td>Responsibility, resources, random or strategic task distribution, leaving the ED, environment and interior design.</td>
</tr>
<tr>
<td>Attitudes towards BID</td>
<td>Importance of BID care, saving lives versus caring for the dead, how do you talk about BID, is BID care complex and why?</td>
</tr>
<tr>
<td>BID relatives</td>
<td>What is the core content of nursing for BID relatives, knowledge and competences, barriers and facilitators?</td>
</tr>
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