

## EMPIRICAL STUDIES

# Family caregivers' experiences of end-of-life care in the acute hospital setting. A qualitative study

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## Abstract

**Background:** Acute hospital settings are generally not considered adequate places for end-of-life care, but terminally ill patients will continue to die in acute medical wards in the unforeseeable future.

**Aim:** The aim of this study was to investigate family caregivers' experiences of end-of-life care in an acute community hospital in Iceland.

**Methods:** Fifteen in-depth qualitative semi-structured interviews were conducted with participants who had been primary caregivers. The transcribed interviews were analysed using thematic content analysis.

**Findings:** Findings indicated that the acute hospital setting is not a suitable environment for end-of-life care. Effective communication and management of symptoms characterised by warmth and security give a sense of resilience. Three main themes emerged: (1) Environmental influences on quality of care; (2) Communication in end-of-life care; (3) The dying process. Each of the themes encompassed a variety of subthemes.

**Conclusions:** Findings suggest that effective communication is the cornerstone of quality of care in the acute hospital environment and essential for establishing a sense of security. The severity of symptoms can deeply affect family caregivers' well-being. Acknowledging and appreciating the meaning of respect and dignity at the end-of-life from family caregivers' perspective is vital.

## KEYWORDS

acute hospital settings, bereavement, communication, end-of-life care, environment, family caregivers, grief, palliative care

## INTRODUCTION

End-of-life care has been defined as a specific component of palliative care aiming to identify and manage suffering when cure is no longer an option, and death is approaching [1]. For a substantial period, various authors have distinguished

between general and specialised palliative care [2, 3], the latter requiring a high level of education, appropriate staff, and other resources [4]. However, health care professionals' perceptions about palliative care have been found to be blurred and confusing indicating the immediate understanding being that palliative care is equivalent to end-of-life care [5].

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Considerable work has focused on bereaved family members during the end-of-life care suggesting that good communication and information about treatment, and mutual understanding between family members and health care professionals are important issues [6, 7]. A study conducted in Iceland revealed that if a personal relationship is established early and family caregivers are adequately prepared for signs and symptoms that may appear near death it can have an impact on how they experience the actual moment of death [6, 8, 9].

Nurses spend more time with dying patients than any other health care profession giving them opportunities to contribute greatly to the outcome of palliative and end-of-life care, built on their professionalism encompassing scientific knowledge, professional skills and humane relations [10, 11]. This is supported in a systematic review of interventions in palliative and end-of-life care [10] demonstrating statistically significant patient or caregiver's outcome for a variety of incurable diseases. The strongest evidence was found in improved communication and care planning involving nurses and social workers.

However, it is important to look at criticism that states that acute hospital wards are not the ideal place to provide end-of-life care where treatment is usually aimed towards cure and not palliation [12].

There is a need for a clearly defined model for palliative care delivery and integration [13] and the fact of insufficient research considering the priorities for palliative care research has also been addressed. In a recent systematic review [14] only ten papers dealing with priority setting relevant across palliative care provision were identified [15, 16]. Moreover, care providers' perspective is prominent in those studies, indicating notable gaps in the priorities relating to quality of life and symptom management [17]. However, previous studies have illustrated that patients in the acute hospital setting view their experiences positively [18] and they may be more likely to have their acute needs met more quickly than in the community. In the acute environment they are directly under the care of a specialist team alongside the palliative care input [19, 20]. This study concentrated on family carers' experiences of end-of-life care in an acute ward in a community hospital in Iceland with emphasis on the environment, communication, symptom management, decision-making and dignity. The number of inpatient hospital deaths in that hospital is approximately 70 on a yearly basis, counting for both chronic and acute conditions.

## METHODOLOGICAL PERSPECTIVES

### Design

A descriptive qualitative approach was selected for this study with a phenomenological approach based on the

ideology of Edmund Husserl regarding the connection between a man's attitude and his experience of a certain phenomenon. The researcher makes attempts to obtain the meaning hidden in the participants' descriptions of the lived experiences [21, 22]. To secure the quality and trustworthiness of the study, the authors followed the three main steps and each sub-item presented in the checklist: Consolidated criteria for reporting qualitative research (COREQ) [23] (Appendix 1).

### Setting

Most deaths in Iceland (54%) occur in hospitals [24]. Iceland has one hospice that only serves a small number of seriously ill and dying patients [25] indicating that the end-of-life care in Iceland is usually provided within the acute setting, in nursing homes, or in people's homes. Specialised palliative care is available in the capital region situated in the south of the country with 228.231 inhabitants, and in a town in the north part of the country serving 19,156 inhabitants as well as the surrounding communities [26]. In the remaining areas health care professionals provide, for the most, general palliative care but can seek advice from specialised palliative care teams situated in the areas mentioned.

### Participants

A purposive sampling method was implemented, the goal was to ensure a sampling of information-rich informants that would provide knowledge and understanding of the phenomenon under study [21]. Every patient who is admitted to a hospital institution in Iceland needs to provide basic information on the person he identifies as his next of kin, and when relevant his primary caregiver, that is registered in his hospital files. In cooperation with the managers of the institution a list of 59 family members who were listed as primary caregivers, was agreed on believing it would meet the aim of the study. The inclusion criteria for the study were: (a) having acted as the primary caregiver before and during the patient's stay at the ward; (b) being 18 years old, or older; (c) being able to understand and answer questions, judged by the nursing managers who knew the family caregivers; (d) being fluent in the Icelandic language; (e) time since death was at least 3 months and not more than 12 months [27]. To secure adequate sample size 19 individuals, who met the inclusion criteria, were chosen from the 59 persons on the list of names obtained, using both stratified and systematic random sampling methods with an even distribution between times since death [28]. All these 19 individuals accepted to participate. This number of participants was

thought to be satisfactory to uncover the variety of experiences and to reach satisfactory saturation [29, 30].

## In-depth interviews

Interviews were conducted with 15 family caregivers by two authors who are both trained interviewers with experience in qualitative study design. By using a semi-structured interview framework (Figure 1) each participant was interviewed once, in their own home, without anyone else present. Specific questions were also used to gain more extensive descriptions and confirm mutual understanding [31]. The interviewer began by explaining the interviewer's interest in the research topic. The duration of each interview ranged from 25 to 60 min.

Although some discrepancies exist on the definition of saturation in qualitative research [29] according to Miles and Huberman qualitative methods place primary emphasis on saturation meaning that the researcher should continue to obtain a comprehensive understanding until no new substantive information is acquired [32]. This definition guided our work when considering whether the sampling of data could be ended after completion of the 12th interview. We chose to carry out three more interviews to confirm that no new data would emerge [30] and the remaining four

persons who had accepted the invitation to participate were informed. Therefore, consequently, recruitment was ceased at 15 participants [29, 30]. Interviews were conducted over a 5-month period in the year 2016.

## Theoretical approach

The key conceptual framework for this study is grounded in Lazarus and Folkman's model of stress and coping. It is theorised to consist in the individual's cognitive and behavioural efforts to reduce, minimise, master, and/or tolerate internal and external demands of the person-environment transactions [33, 34]. Coping with external demands is seen as serving two major functions: (1) problem-focused coping, i.e. trying to change the stressor by dealing constructively with the problem that is causing the distress, and (2) emotional-focused coping, i.e. the effort to manage a stressful situation by trying to regulate the emotions via changes in the perceived meaning of the stressor itself [33, 34].

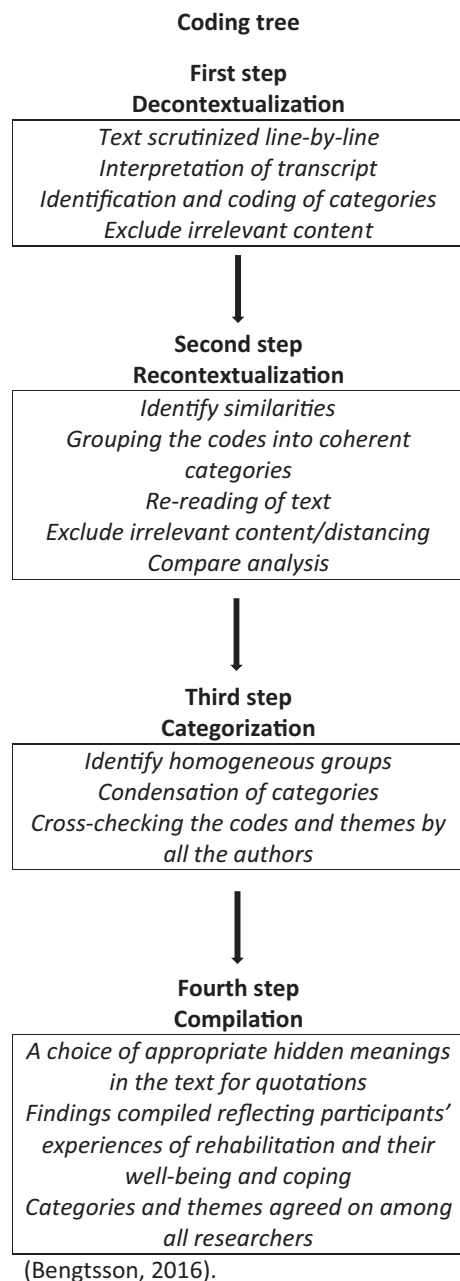
## Data analysis

Interviews were audio-recorded, transcribed verbatim, conceptualised, and coded, and each transcript was given

<p><b>Q1. Could you begin by generally describing your experiences of end-of-life care?</b></p> <ul style="list-style-type: none"> <li>• <b>Further probes:</b> <ol style="list-style-type: none"> <li>1. I would like to ask you about your experiences of end-of-life care at the ward?</li> <li>2. What is it that you consider as most important in end-of-life care?</li> </ol> </li> </ul> <p><b>Q2. Can you tell me about your experiences of the environment on the ward regarding end-of-life care during the time we are referring to?</b></p> <ul style="list-style-type: none"> <li>• <b>Further probes:</b> <ol style="list-style-type: none"> <li>1. Are there any specific environmental issues that have a negative impact on the quality of end-of-life care? If so, can you clarify?</li> </ol> </li> </ul> <p><b>Q3. Can you tell me about your experiences of communication with nurses and other health care professionals on the ward during the time we are referring to?</b></p> <ul style="list-style-type: none"> <li>• <b>Further probes:</b> <ol style="list-style-type: none"> <li>1. In your opinion – what is characterized by so called good communication in end-of-life care?</li> <li>2. What is your own experience of communication with nurses and other health care professionals during the time we are referring to?</li> </ol> </li> </ul> <p><b>Q4. Can you tell me about your experiences of symptom management during the time we are referring to?</b></p> <ul style="list-style-type: none"> <li>• <b>Further probes:</b> <ol style="list-style-type: none"> <li>1. Management of pain? Nausea? Anxiety? Other symptoms?</li> <li>2. What do you consider to be a good management of symptoms in end-of-life care?</li> </ol> </li> </ul> <p><b>Q5. Could you describe to me how decisions were made about commencing end-of-life care i.e., from palliative- to end-of-life care?</b></p> <ul style="list-style-type: none"> <li>• <b>Further probes:</b> <ol style="list-style-type: none"> <li>1. What would you like to emphasize regarding that decision?</li> </ol> </li> </ul> <p><b>Q6. Can you tell me about your experiences of dignity - shown to your loved one and to the family - by the health care professionals on the ward during the time we are referring to?</b></p> <ul style="list-style-type: none"> <li>• <b>Further probes:</b> <ol style="list-style-type: none"> <li>1. How would you explain dignity in end-of-life care?</li> <li>2. What is – in your opinion on – 'to die with dignity?'</li> </ol> </li> </ul>
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**FIGURE 1** Interview guide used by the interviewers

a number to ensure anonymity. Four stages of content analysis guided the process of coding of the text: decontextualisation, recontextualisation, categorisation and compilation [35] (Figure 2). The transcripts were read line by line independently by two authors, to get a clear and cogent understanding of the overall contents [30, 35]. Codes were found and grouped into coherent categories, each of which was given a name or a code, to prepare for a thorough examination and understanding of the underlying meanings of the text thus obtained. The quality and trustworthiness of the analysis was then secured by all the authors who discussed the codes and categories, until a final consensus was reached. Descriptions with



**FIGURE 2** Coding tree

similar meanings or related topics were agreed upon by the researchers resulting in a formulation of main themes and sub-themes (Figure 3) reflecting the relationships and interaction between the codes related to the participants' descriptions of their experiences [35].

## Ethical consideration

The Icelandic National Bioethics Committee approved the study (Ref: VSNb2014110026/03.07). Permission was obtained from the managers of the institution to establish contact with prospective participants. Participants were given a written description of the study including an explanation of their rights as participants, confidentiality, voluntary participation, and freedom to withdraw from the study at any time without consequences. Informed consent was obtained from all participants prior to the interviews.

## RESULTS

Most of the participants were women [10] (Table 1). The following three main themes emerged from the data: (1) Environmental influences on quality of care; (2) Communication in end-of-life care; (3) The dying process. Each of these themes encompassed a variation of subthemes relating to participants' perceptions and experiences of being a primary family carer in the end-of-life care situation (Figure 3).

### Theme 1. Environmental influences on quality of care

Environmental factors were found to influence a variety of issues referred to as "the quality of the service," by all the participants. The interview data revealed a strong need for a quiet and relaxing environment, for both the patients and family caregivers.

#### Sub-theme: Need for privacy

All participants emphasised the importance of having a private place where they could be with their loved ones. They claimed that commotion and disturbances were a common thing in the ward described as "being in a train station". It was also important to have a private place inside the hospital ward environment where family caregivers could come together and discuss issues that could not be spoken about at the bedside. The discomfort and

**FIGURE 3** Meaning units, condensed meaning units, sub-themes and main themes: Extracted from participants' descriptions about experiences of end-of-life care in an acute hospital setting

Core theme: Security and professional care provided with dignity and respect has an impact on family caregivers' experiences of end-of-life care, and the actual moment of death			
Meaning unit	Condensed meaning units	Sub-themes	Main themes
<p>"The environment is bothering you, and you feel like you are bothering the environment"</p> <p>"... and you feel like you are in a theatre ... you are crying somewhere in the hallway in front of a lot of people"</p> <p>"One felt a kind of peace and quiet inside the room, this was just like a hospice room in all the chaos"</p>	<p>A feeling of inconvenience – of 'being in the way'</p> <p>Lack of privacy generates feeling of frustration and anxiety</p> <p>The importance of quietness - for the patient and family caregivers</p>	<p><i>Need for privacy</i></p> <p><i>The efforts of health care professionals</i></p>	<p><b>Environmental influences on quality of care</b></p>
<p>"... he also got a bed beside her - when she was leaving us - I also stayed with her - I found that very comforting"</p>	<p>The value of closeness at the end-of-life</p>		
<p>"I do not know how I would have been able to get through this if it had not been for them [the nursing staff] ... this was personal, I thought it was good"</p> <p>"This is priceless, you felt that he [the nurse] was a participant in the process"</p>	<p>Meeting the needs of the patient and his loved ones in a caring and sensitive manner</p> <p>The importance of establishment of interpersonal relationship enhances trust and a feeling of security</p>	<p><i>The importance of nurses' presence</i></p>	<p><b>Communication in end-of-life care</b></p>
<p>"This is how it works, then you experience so much professionalism and security"</p>	<p>Precise and adequate flow of information provides a sense of security</p>	<p><i>Information and professionalism</i></p>	
<p>"He was just put-on so-called end-of-life care - we did not understand - we did not know"</p> <p>"... you sense that a staff member is insecure - then you become insecure - probably a lack of experience"</p>	<p>Lack of information of patient's imminent death causes insecurity - family carers take on the 'heavy burden' of informing a loved one</p> <p>Lack of discipline – lack of professional experience – enhances feelings of insecurity</p>		
<p>"Right before the end these lines and machines were not working - he was not getting his medication - no peace and sleep - that I found very difficult"</p>	<p>Watching a loved one suffer - while having to be strong and protective – awakens a feeling of helplessness against the situation</p>	<p><i>The impact of symptom burden on the family/the feeling of helplessness</i></p>	<p><b>The dying process</b></p>
<p>"... you need to know the will of the dying patient - give people the permit to leave - to be able to let go"</p>	<p>Peace and tranquillity before and at the actual moment of death – performing care in a beautiful and sensitive manner</p>	<p><i>Dying with dignity, and care at the end-of-life</i></p>	
<p>"I would have liked more time with him - I somehow felt that he had been taken away - even though he was still there"</p>	<p>Difficult and shocking - facing the truth - the person was gone - and was not coming back</p>		

**TABLE 1** Demographic characteristics of the sample

Gender
Women (10)
Men (5)
Age range (40–80)
Diagnosis
Cancer 13
Stroke 2
Primary carer for spouse (7)
Primary carer for parent (8)
Time range from admission to death 1–12 weeks
Time since death 3–12 months

insecurity when having to mix socially with other patients and their relatives was causing anxiety. It was also difficult to be in the situation of having to repeat information to other people on how things were progressing:

The environment is bothering you, and you feel like you are bothering the environment  
(Participant, 6).

You know some people from somewhere, I mean, some people you don't necessarily want to meet at this point in time. With that in mind it would have been better to be more private  
(Participant, 4).

Another participant who had experienced anxiety and the frustration of having to display her anguish and grief in an open space inside the ward explained that sometimes one simply needed privacy to cry:

But you know, everything is open for everyone, and you feel like you are in a theatre, even though you exclude a lot of things, you know, you just don't think about the fact that you are crying somewhere in the hallway in front of a lot of people, it's a different feeling than if you had privacy  
(Participant, 13).

### Sub-theme: The efforts of health care professionals

It was highly appreciated when the nurses tried to manage effectively specific aspects of end-of-life care within the acute environment. This positive experience of nursing

care depended on the compassionate attitudes shown by nurses and how sensitive and understanding they were to the patients' problems. When family caregivers were in a situation they could not control, were vulnerable, and did not even know what was ahead, personal acquaintances with staff and trust and guidance had a positive influence. It mattered a great deal. One stated that despite commotion on the ward the nurses had managed to make a peaceful environment inside the hospital room:

One felt a kind of peace and quiet inside the room, yes, I mean, this was just like a hospice room in all the chaos  
(Participant, 5).

Most participants agreed that health care professionals were attentive and caring despite the lack of facilities for the family showing great concern, kindness and consideration. Suggesting or offering something extra to ease the burden and exhaustion was highly valued and helped the family to sustain the long hours they often spent with their loved one, not considering their own needs. One participant recalled fondly when beds were pushed together to make one big bed:

I also found it very comfortable that me and dad could stay with her [mother], he also got a bed beside her and when she was leaving us I also stayed with her, I found that very comforting  
(Participant, 12).

## Theme 2. Communication in end-of-life care

Establishment of a relationship between family caregivers and health care professionals enhanced feeling of security and that they were respected and secure in the environment. This was described as the key elements in end-of-life care and had a big impact on their experience of the end-of-life care process.

### Sub-theme: The importance of nurses' presence

Most participants felt that nurses' conduct and attitudes were exemplary which portrayed human intimacy in their communication. The importance of nurse's presence was explained as a need for a warm and strong presence, felt immediately as soon as a nurse entered the hospital room and took part in the process with the family. A warm touch from the nurse to the patient meant showing the loved one "respect", making it possible for the family to

experience the passing of their loved one as a beautiful moment, although being inevitable and sad:

I do not know how I would have been able to get through this if it had not been for them [the nursing staff] if I had been somewhere else, this was personal, I thought it was good  
(Participant, 3).

This is priceless, you felt that he [the nurse] was a participant in the process, and not just someone in a white robe who was just doing his job

(Participant, 7).

Negative experiences were explained as lack of satisfactory communication and disrespect intertwined with lack of presence. Nurses did not provide adequate time to care for the patients, nor did they check in on the patients according to needs. It was not seen as satisfactory if they just popped in and asked if everything was alright. This led to a feeling of a lack of support and insecurity for the family caregivers, leaving them bewildered and struggling to understand if their loved one had been abandoned or simply forgotten. This was experienced as a great lack of respect towards their loved ones who were in a vulnerable situation causing feelings of irritation and frustration in both the family caregiver and the patient.

### Sub-theme: Information and professionalism

The importance of precise and adequate flow of information played a significant role in the communications between family caregivers and health care professionals. They experienced a sense of security when they were informed and consulted about patients' symptoms and decision-making about treatment. If they sensed that their loved ones valued the quality of care and service as much as they did, they were satisfied:

This is how it works, then you experience so much professionalism and security  
(Participant, 6).

Yes I am very happy with the service we received, everyone was so good and kind and ready to do everything for her and us  
(Participant, 11).

For some family caregivers it was important that health care professionals discussed with them their loved one's

imminent death more candidly and in detail, they were not always aware of the fact that death was near, and neither was the patient himself. In such cases some participants had experienced that they had to take on the "heavy burden" to inform and discuss this issue with their loved one which was "extremely difficult" for them. Lack of professionalism and information sharing on behalf of the doctors was also explained, leaving the family with unanswered questions creating a lack of trust and influencing their experiences of end-of-life care heavily. Some participants linked negative experience to lack of discipline, and that inexperienced health care professionals who cared for their loved ones could cause insecurity:

He was just put on so called end-of-life care, we did not understand and we did not know  
(Participant, 13).

As soon as you sense that a staff member is insecure, then you become insecure, I feel it is very important that I sensed it, probably a lack of experience

(Participant, 7).

### Theme 3. The dying process

The impact of the multiple symptoms upon the patient affected the family caregivers' psychological well-being enormously. Not being able to relieve the symptoms was unbearable but trying to suppress these feelings just made them sad and miserable. This was intertwined with feelings of loss and grief throughout the time of symptom management becoming more intense when end-of-life care took over. After death, distress and grief were continuously present. Some family caregivers described it as positive for them if the patients had been ready to die.

### Sub-theme: The impact of symptom burden on the family

For many family caregivers having to watch their loved one being so weak and vulnerable while at the same time they had to be strong and protective, made them feel helpless in the situation:

Right before the end these lines and machines weren't working, he wasn't getting his medication, so he was waking up, wasn't getting his pain medication and no peace and sleep, I found that very difficult

(Participant, 13).

Most participants knew what was about to happen when death was approaching and were in that sense prepared for the event. How each one experienced their loved one's last moments differed greatly. Previous experience of such situations along with what had occurred throughout their journey in the end-of-life care did affect how family caregivers reacted and managed in that situation.

### Sub-theme: Dying with dignity and care at the end-of-life

In the participants' description the importance of respecting human dignity when a person is dying appeared throughout the text. Respect was inherent in how their loved one had lived, respect was in life itself, and what their loved one left behind. For the family caregivers' dignity meant that everything was done as beautifully as possible when caring for the dying. If there was peace and tranquillity before and at the actual moment of death, and symptom management was satisfactory, this felt as being an integral part of end-of-life care:

I think that this is also the responsibility of the relatives, you need to know the will of the dying patient, try and meet his will, not to extend something for myself, for us, rather give people the permit to leave, death is part of life, you know, to be able to let go

(Participant, 7).

All the participants were satisfied with the care and kindness they received after their loved one's death and many recollected fondly moments after death had occurred:

... just the attitude in general, then during the end when everything was over, then they brought a table on wheels full of baked goods and coffee, the family was all there in such peace and quiet, I particularly liked that

(Participant, 1).

Family caregivers expressed that they would have wanted to have a longer time with their loved one after death had occurred, before staff started to wash and prepare the body to be taken away. This was illuminated more clearly explaining how difficult and shocking it was having to face the truth. Their loved one had gone and was not coming back.

I would have liked more time with him before they started preparing him, just to have had more time in there with him, even though nothing had been done, I somehow felt that

he had been taken away even though he was still there

(Participant, 13).

## DISCUSSION

The aim of this study was to explore family carers' experiences of end-of-life care in an acute medical ward. Results clearly indicate the need for a quiet unrestrained environment and the needs of the family must always be considered when end-of-life care is planned and provided. The commotion known to be present in acute wards and various other issues can adversely affect family carers of a dying patient [6]. Thus, factors causing distress or even anxiety should be prevented or managed. In this study, all the participants emphasised the importance of good communication and the impact it had on their experience of the process.

### Environment

It is urgent to acknowledge the fact that hospitals are and will continue to be an optimal place for end-of-life care [24, 36]. Results in this study add to the current knowledge about the impact the acute environment within hospitals may have on family caregivers, caring for a loved one at the end of life [36, 37]. Findings also suggest that lack of privacy and not being able to avoid socialising with other relatives can cause anxiety and feeling of insecurity. Despite the negative influence the acute environment can have on family caregivers of a dying individual it can also in some ways be suitable. It may be possible for some family caregivers to experience security, peace and quiet from all the hustle by just closing the door behind them, to "create their own oasis in the desert". In this study, it became apparent that communication and the establishment of a good relationship was closely intertwined with how well the family carers adjusted to the environment during this time of loss and grief [9]. Findings also correlate with previous findings suggesting that nurses are skilled in figuring out and executing solutions to better meet the different needs of patients and their family members, despite the unavoidable hectic atmosphere in the acute setting [18, 37].

### Communication

This study brings new light on the power of communication and the establishment of interpersonal relationships in end-of-life care, described as having an influence on the



family caregivers' experiences of the process. Establishing interpersonal relationships in the acute environment characterised by limited privacy and interruptions may be difficult [6, 37]. It was not found to be problematic in this study showing that most of the participants had managed to form that kind of a relationship. Nevertheless, issues directly affecting patient's well-being leading to worries and distress were related to incomplete communication, lack of nurses' presence when the caregivers needed it, and disrespect leading to a loss of dignity for the patient. This suggests that there is a need for advanced education for nurses working in this discipline allowing them to concentrate on family members' strengths and vulnerability earlier in the care planning process and throughout [38]. Supporting patient's dignity encompasses first and foremost nurses' perceptiveness towards the patients, their ability to communicate effectively, manage symptom control and secure that patients and their caregivers are active participants in decision-making about their treatment and well-being [39].

Effective communication between patients, family members and health care professionals is a prerequisite for being able to provide appropriate care at the end-of-life [9, 40]. This corresponds with findings in our study indicating that the human factor is the most important factor in the whole process, having more weight than if the ward is an acute medical ward or a long-term ward. The health care professionals' conduct and attitudes were portrayed by human intimacy in their communication [40]. Findings also indicated that end-of-life care ought to be organised and structured as being a service operating within a framework that would prevent failure and reduce the risk of patients being neglected or forgotten. Although there is a lack of more recent studies on the neglect of patients in end-of-life care, there is a reason to consider this as a possibility. Nursing requires scientific knowledge, professional skills, and humane relations [11] and nurses spend more time with dying patients than any other health care profession [10]. That said, there is a reason to give specific attention to those who are inexperienced in caring for those who are dying and their families [37].

## The dying process

Findings in this study call for further investigation on the impact symptom burdening and the patient's distress and discomfort has on the family carers. The results in this study that demonstrate feelings of helplessness and frustration in the family are supported by findings in previous studies suggesting that family caregivers identify symptom management as the most difficult issue [7, 41]. It has been suggested that perceptions of inadequate symptom

management in hospitals might be related to the fact that unpredictable diseases are more common among hospital patients, and patients are younger compared to individuals in other settings of health care [41]. Additionally, it may depend on the family caregiver's understanding of the disease and how the news of the diagnosis is delivered [42].

Results in this study are in accordance with previous findings indicating the importance of mutual understanding between the family caregivers, patients, and health care professionals and how well they had been prepared and warned about any changes in the situation prior to the patient's death [7, 40]. There are also similarities in our findings and results in a study showing that maintaining human dignity in end-of-life care, to be treated with respect until the end, is of utmost importance [39]. Dignity and autonomy are closely connected and death with dignity applies to how the individual had lived and what he left behind [43]. This indicates that the role of the nurse and other health care professionals is, therefore, not to confer on patients either dignity or death with dignity, but to ensure that dignity is maintained. In this study, results can be seen to reflect the above definitions of dignity suggesting that participants were satisfied with how the nurses showed their loved one respect and nursed him with dignity. This was again related to the power of communication and the establishment of interpersonal relationships in the process of end-of-life care.

Participants' descriptions in our study provide some support for Lazarus and Folkman's conceptual framework of stress and coping [34] although some participants could not deal actively with the problem on their own [33, 34]. Thus, findings in our study call for further investigation on how nurses and other health care professionals can best support family caregivers of a dying person to reduce, minimise or master the internal and external demands [33, 34]. Furthermore, our findings cohere with Husserl's phenomenological approach [44] which was used as the philosophical underpinning for this study since its purpose was to describe human experience as it was lived by family caregivers during end-of-life care. Husserl's idea was to describe lived experience and by using phenomenological reduction get at the pure essence of the phenomenon, by bracketing the presuppositions of experience we are able to get the pure phenomena from the participants' descriptions [44].

## Strengths and limitations

The retrospective method used in this study can be a limitation in the sense that people can find it difficult to recall events since the loss which can affect the result.

To minimise this possibility and to secure the accuracy of the data, interviews were not conducted too close to the death and the time from death was not too long [27]. The fact that participation was voluntary may be a limitation, pointing to a possible self-selection bias in the sample. It should be noted that interviews were performed in 2016 and there are various reasons causing the delay in the completion of this manuscript, one is the COVID-19 pandemic. However, the fact that the care has remained substantially the same since data collection should not be considered a limitation. Finally, the absence of member checking should be considered as a limitation, in this study it was not an option.

## CONCLUSIONS

Findings in our study may benefit nurses and other health care professionals when caring for terminally ill and dying patients and provide insights that are of relevance to a regional or international context. Findings indicate that environmental factors in the acute environment can influence the quality of the service while it was also found that the acute environment characterised by limited privacy and interruptions does not necessarily limit the quality of care or have a negative impact on the family's expectations. Effective communication is the cornerstone of quality of care and the fundamental part for establishing a positive and fruitful relationship and sense of security. The severity of the symptoms and the impact it had on the patient deeply affected the families' own well-being during end-of-life care, calling for increased attention to this aspect of care. Furthermore, findings confirm the importance of acknowledging and appreciating the meaning of respect and dignity at the end of life as seen from family carers' perspective.

## ACKNOWLEDGEMENT

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## CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

## ETHICAL APPROVAL

The Icelandic National Bioethics Committee approved the study (Ref: VSNb2014110026/03.07).

## AUTHOR CONTRIBUTIONS

Svala Berglind Robertson, designed and coordinated the study, recruited the participants, collected data, performed analysis, interpreted data, and contributed to the drafting of the manuscript. Elísabet Hjörleifsdóttir, participated in

the design and coordination of the study, contributed to data analysis, interpretation of data, and various drafts of the manuscript. Þórhalla Sigurðardóttir, contributed to data analysis, interpretation of data and the final draft of the manuscript.

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## APPENDIX 1

### COREQ (Consolidated criteria for Reporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	SBR and EH
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	MSc, PhD, Prof
Occupation	3	What was their occupation at the time of the study?	See Title page
Gender	4	Was the researcher male or female?	Female
Experience and training	5	What experience or training did the researcher have?	See covering le
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	N/A
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	5
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	5
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	3,5,6,16
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	4
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	4
Sample size	12	How many participants were in the study?	4
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	5
Presence of non- participants	15	Was anyone else present besides the participants and researchers?	5
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	4,6, and Table 1
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5, and Figure 1
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	5,6

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Field notes	20	Were field notes made during and/or after the inter view or focus group?	N/A
Duration	21	What was the duration of the inter views or focus group?	5
Data saturation	22	Was data saturation discussed?	5
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	17
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	6
Description of the coding tree	25	Did authors provide a description of the coding tree?	6, and Figure 2
Derivation of themes	26	Were themes identified in advance or derived from the data?	6-13
Software	27	What software, if applicable, was used to manage the data?	N/A
Participant checking	28	Did participants provide feedback on the findings?	17
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	6-13
Data and findings consistent	30	Was there consistency between the data presented and the findings?	6-13
Clarity of major themes	31	Were major themes clearly presented in the findings?	6,13, and Figure 3
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	6-13

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349–357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.