

Research Article

The Room as Metaphor: Next-of-Kin's Experiences in End-of-Life Care

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The "room" in end-of-life is a phenomenon that needs deeper understanding as it is a dimension that shows how health and suffering are shaped. Research on the concept of room was chosen as theoretical foundation in this study in order to reach a profound understanding of the next-of-kin's "room" in end-of-life care. Lassenius's hermeneutic interpretation in metaphorical language was used as an deductive-inductive approach to the empirical data. The data material comprised 33 interviews with next-of-kin about their experiences of end-of-life care when being close to a relative dying from a cancer disease. The analysis of the data formed four cases: the Standby, the Asylum, the Wall, and the Place. These cases lend their voices to the experiences of the next-of-kin in the study. The findings of this study explain and may well assist nurses to understand the experiences of being next-of-kin in end-of-life care as forming a room of rest from the suffering, a room of controlling the suffering, a room of hiding from the suffering, and a room of belonging.

1. Introduction

As next-of-kin, confronting end-of-life entails a complex life-situation. To be standing face to face with death can involve a suffering that is difficult to cope with [1]. Next-of-kin can express loneliness in the end-of-life situation. This can emanate from apprehension when it comes to sharing their fears and thoughts with others [2]. Bruce et al. [3] observe that in the process of engaging in existential suffering in end-of-life, there can be a longing for ground in a groundless world; this means a wish to reduce the uncomfortable instability when faced with terminal diagnosis. To minimize the discomfort or anxiety-provoking instability that the situation creates, Bruce et al. [3] relate three possibilities, as follows: facing the discomfort and letting go, turning from the discomfort in an attempt to keep it at a distance, or living within the instable and unknown. This can correspond to the descriptions of the sickroom, as a place that provides boundaries that can give protection and security, thereby allowing space for the unfathomable, but it can also be

connected with insecurity, experienced as losing foothold and a cry for belonging to something secure in life [4].

Emotional stress can be part of the next-of-kin's situation due to an imminent loss of a loved one. This stress can also be caused by the responsibility for participating in the care [5]. It has been showed that next-of-kin who are involved in end-of-life care can be seen as a backbone of the delivery of health care and social care services [6, 7]. This is something that Andersson et al. [5] describe as being not only practical matters but also involving emotional experiences, such as worries and limited freedom, as well as satisfaction. There can also be vulnerability in the situation when death is an impending threat. The next-of-kin's experiences of challenges and burdens can involve intense, conflicting, negative, and difficult emotions [8]. Despite these experiences it appears to be an ambition to maintain control and be present [9, 10]. Being next-of-kin in end-of-life care can thus be seen as an experience where both feelings of satisfaction and feelings of not being able to cope with the situation may emerge [11]. Next-of-kin can also struggle with existential

issues and suffering [12]. There is often a commitment to make the remaining time for the dying person as good as possible. Hebert et al. [13] show that next-of-kin need support from health care personnel in order to prepare themselves for the impending loss. The preparedness needs to have cognitive, affective, and behavioral dimensions. Next-of-kin might require information that is personalized to their uncertainties (cognitive), might need to be emotionally prepared (affective), and might have important tasks to finish (behavioral).

It is important to elicit deeper knowledge about what it is like to be next-of-kin in such a context. In order to widen the understanding of the next-of-kin's situation in end-of-life care we were inspired by Benner's thinking about paradigm case [14] as well as Lassenius's [15, 16] thinking about "the room." Room has ontological qualities pointing at being situated by a person (p. 93). The room may in this sense be regarded as man's existential address. Further the room can include a motion between meaningful closeness and meaningless distance as well as between intimacy and infringement [15, 16]. This study is an attempt to assess the research on the concepts of "the room" in a caring environment, as a way of understanding of the suffering of the next-of-kin in end-of-life care. The space is a fundamental dimension that affects how health and suffering are shaped, as well as how health and suffering influence "the room." Research shows that the end-of-life period can be a time of suffering for the next-of-kin [1, 8]. What the person is in the experience of his/her situation of being next-of-kin in end-of-life care is connected to the experience of "the room." The world outside can be reached through a door and this door can lock out the outside world, which might be seen as a threat, but it can also lock in the person in the room [15, 16]. Thus, the room is not always a caring consolation that offers protection (cf. [17]). The room may also lack meaning and be nonprotective.

The room can be seen as a space that deals with the most fundamental aspects of being human. Caring for a person therefore means not only caring in a room, but also creating room for the other [15, 16]. According to a life-world approach [18] the room has a meaning that is unique for every person. It can include the experience of being an anchor of existence, not least when a person experiences helplessness and disorientation. It is important to have a foothold of continuity and predictability. Werkander Harst de and Andershed [19] discuss the importance of safety, participation, and trust in end-of-life care. If these qualities are established they can be interpreted as a form of anchorage. Research on the meaning of room is fundamental when it comes to mediating end-of-life care. This implies that the care and the experience of room are intertwined phenomena. The question is how and in what way this intertwining creates meaning to the room in end-of-life care. Furthermore the question is how this meaning is experienced by next-of-kin.

Lassenius [15, 16] has investigated the semantic meaning of "the room" in accordance with caring and found that it involves three entities with ontological meanings: First, it is an ideal and mutual creation in the freedom of being and becoming health. It involves freedom, sovereignty, choice,

and dignity to the human being. Second, the room represents a kind of frozenness of despair where the drama of suffering takes place. Finally, it represents the very core of the person's inner and outer location as a kind of at-homeness and rootedness. It is through connecting these three entities in a drama of suffering that the room is shaped as ontologically good and meaningful in the world of caring. Dictionaries confirm that the concept room is generally referred to as a physical room [15, 16]. The question is if there is more meaning in the concept of room in this context that can contribute to a more profound understanding of being next-of-kin in end-of-life.

In the room there can be a *Standby*, a temporary place with the possibility of resting if the burden is too much to cope with. It is also a passage where the suffering is suffered. In the *Standby* possibilities are created but also the opposite. The world outside can be experienced as a threat and the *Standby* offers a room to escape to.

When a person lacks the courage to get in touch with her/his inner suffering the strategy to escape to *the Asylum* develops. The *Asylum* indicates a more long-standing hide-away or withdrawal. It can be seen as a shelter where the person can face her/his suffering or keep it away, if it is too intense.

The Wall comes forth when existence urges the person to develop according to her/his inner desires. It is formed when the person experiences an advanced stage of constant feeling of suffering and can be seen as a containing space for this insufferable and pointless suffering. The Wall then becomes a protection against this suffering.

Finally, *the Place* is a vague feeling of "at-homeness" created when the person is searching for meaning. This search involves a quest for something that can be called one's own, something to belong to, and it requires participation. Through the place's spatiality the person can participate in the world and at the same time reconcile with the past [15, 16, 20]. For nurses this is an important clinical knowledge that can contribute to the understanding of the room.

Aim. With this background, the aim in this paper is to explore the meaning of "the room" as experienced by next-of-kin in end-of-life care.

2. Materials and Method

2.1. Material and Participants. The empirical data material consists of 33 interviews with next-of-kin to persons who died from cancer. Next-of-kin, as a concept in a Swedish context, is seen as a person who is involved in the care for the ill person. This person can be a blood relative, someone who is married into the family, a cohabiter, or a close friend. It is someone that the person who is ill considers she/he is closest to. In this research the next-of-kin was a spouse or an adult child. The interviews followed 17 next-of-kin during the first year after they lost their loved ones. Each interview took between 45 minutes and 1,5 hours to conduct. Most of the interviews were conducted at the homes of the next-of-kin; four informants wanted to come to the researcher's office for the interview. The goal was to carry out three interviews with

every informant. The first interview took place approximately three months after the death and then after approximately six months and again after one year. Most of the next-of-kin were interviewed three times, some twice, and two persons once. The reasons for the lack of follow-up interviews were that one person died during the first year, one person moved away without leaving a new address, and in some cases it was not possible to arrange three interview sessions. The interviews were designed to allow the participants to talk about what it was like to be next-of-kin in end-of-life care and how the situation evolved through the first year after the death of the loved one. These interviews are part of a larger project, "Guilt and Shame in End-of-Life Care – The Next-of-Kin's Perspective" where the focus has been experiences of guilt and shame. The data material has previously been used in two studies [21, 22] and in the doctoral thesis [1]. Since the data material emphasizes not only experiences of guilt and shame but also the whole situation of being next-of-kin in end-of-life care it was considered to be credible also for this study to explore the meaning of "the room" as experienced by next-of-kin in end-of-life care.

2.2. Ethical Considerations. Ethical approval for the study was obtained from the Regional Ethical Review Board in Stockholm, Sweden (2008/1223-31). Written consent was obtained from all participants and a right to withdraw that consent was ensured. A social worker was available for the next-of-kin if needed, for discussion if the interview was emotionally difficult to handle.

2.3. Analysis. We used a qualitative deductive-inductive approach for this study. The motive for this choice was that qualitative design would be most appropriate when interpreting the meaning of experiences. A deductive approach was selected because the research-phenomenon, "the room," is abstract and therefore needs to be explored accordingly. This means that the research focus was on the "what" and not on the "how." The deductive approach also means that conclusions must be drawn empirically [23–25]. In this study we used metaphors from Lassenius's [15] doctoral thesis. These abstract, interpreted concepts were employed to analyze the empirical data of next-of-kin's experiences of end-of-life care. The reason for this choice was the assumption that Lassenius's hermeneutic interpretation of the meaning of room can contribute to a deeper understanding of what the meaning of the experience of room is at an ontological level in this specific context, being next-of-kin in end-of-life care.

Deductive-inductive analysis is described in certain steps that correspond to the performance of the analysis. First, the deductive aspect of the analysis meant to search for certain metaphors. These were the Standby, the Asylum, the Wall, and the Place, as described above in the introduction. According to Ricoeur [26], metaphors have a surplus of meaning, and therefore their analysis corresponds to the aim of this study, namely, to investigate the meaning of room in end-of-life care.

The second phase involved inductively searching for patterns. Meaning units that corresponded to the metaphors

were used. These metaphors were searched for in the data material. Similar and different patterns in accordance with the aim of the study were identified. These patterns formed four dimensions of next-of-kin's experience of what "the room" in end-of-life care means. These dimensions were illustrated in four narratives by four fictive next-of-kin (cf. [14]). The findings were then referred back to the empirical data in order to validate the new understanding of room in end-of-life care.

The narratives are accordingly described as Anna's room, Ben's room, Sam's room, and Maria's room. These rooms contain patterns that were elucidated in the deductive analysis and the subsequent inductive analysis of the empirical material. This may be described as a case method. However, Van Wynsberghe and Kahm [27] hold that "case based method" is not a method, a methodology, or research designs. Instead it is transparadigmatic, which means that case study is relevant regardless of the research paradigm. The case study offers a means of investigating complex social units consisting of multiple variables of potential importance when understanding the phenomenon [28, 29] distinguishes case study from methodology not as a methodological choice but a choice of what is to be studied. Furthermore Anthony and Jack [30] state that case studies have become established in nursing research as a well-accepted methodology to address the phenomenon of caring. In this study, the phenomenon "room," seen in a caring perspective, may be compared to Karlsson et al. [31] as a complex phenomenon that incorporates all data into the analysis and arranges it as a coherent narrative [31].

3. Results

The findings are presented according to the aim of the study and the result of the analysis as the experience of room by next-of-kin in end-of-life care. The room "type" is exclusive but the connections with the other rooms are changeable according to the development of next-of-kin's suffering. In that way it is possible to move between rooms.

3.1. Anna's Room: The Standby. Anna is a young woman whose father died due to bowel cancer. It has been a roller coaster experience. Anna narrates the experiences when being told by the doctor about her father's illness: "I heard what the doctor said but still I did not hear. I did not want to hear because if I did not hear, it was not true." For Anna the room represented a place where she could stay away and rest from the trying life-situation. She could escape into her "Standby" temporary because when she was there she could put the outside world aside for a while. It helped Anna to process what was happening.

Even though she was mostly confident with taking care of her dying father there were moments when everything became too much. She felt that she could hardly breathe. When someone else, for example, the nurse, took over her responsibilities she escaped into her Standby room, away from everything. Even though it was just for a short while it helped her gather strength to go back to her ill father.

When her father died Anna was devastated. She could not sleep and her mind was occupied with her father's death. The only way she could handle the situation was to invite her closest friend into her Standby room and in front of her cry, scream, and curse the situation. Her friend listened and that made the grief manageable to handle for a while. By having the opportunity to step inside the "Standby" room she could rest from her suffering; however it was a temporary relief.

3.2. Ben's Room: The Asylum. Ben is an older man who has lost his wife due to pancreatic cancer. He felt that he was right in the middle of what was happening. He followed his wife to doctor's appointments as well as to her treatments. He kept control over time schedules and medications. Ben narrates how he watched his wife suffer without being able to do anything about it except being there and try to comfort her. "Physically I was there and I seemed to handle it OK. People around us, friends and relatives, told me that I was solid as a rock, she was lucky to have me because I took care of everything and I was always there for her. But emotionally I was numb, it felt like being in another place. In that way I managed to put the trying situation away from me, I did not deal with it, I felt so empty inside because there was no other way I could handle it. If I had allowed myself the tiniest bit of feelings it would all fall apart. It was a question of survival. I needed to go as far away from the emotions as possible. I plunged into work and did everything I could to prevent me from thinking about what was happening. I forced myself into routines. It was to survive but it was not to live".

In Ben's room both he and his wife were present. His way of being able to be in "the room" was to escape from the suffering by emotional withdrawal from what was actually happening. The only way for him to endure was to concentrate on specific tasks. This way of dealing with the situation, by not letting changes take place, was an attempt to bring back the old room where he and his wife used to be before her illness. Now she was on her way out of "the room" and he desperately held on to her and to the way their life used to be. The Asylum became a long-standing hideaway and shelter from the suffering that was too intense.

3.3. Sam's Room: The Wall. Sam, a middle aged man, has lost his wife due to breast cancer. He and his wife had come to some sort of mutual understanding not to mention anything about the situation they were dealing with: "If you do not talk about it, it does not exist". The sorrow is hard to handle and Sam did not want to upset his wife. "She will be sad if I am sad, so instead we hide behind this wall and the sorrow cannot reach us." In Sam's room both he and his wife were present and they both built a wall around themselves by not dealing with the wife's illness and dying. They believed that the denial would shelter them from suffering.

The last days of her life Sam's wife had to leave the room and go to the hospital. Sam's choice was not to leave the room. "I could not handle it so I did not visit her. I was not there when she died and I did not see her afterwards. Instead of dealing with the situation I fled from it." Sam was hiding behind something that could be seen as a wall. A wall that prevented him from dealing with the sadness.

After the death of his wife Sam did not care about anything. He did not plan her funeral. He did not clean the house or sort his wife's things. Everything was left as it was. He chose to leave the room but he kept the wall around himself. "If I closed the door I could not see it and therefore it did not exist. Instead I buried myself in work." The Wall was a safe haven from Sam's suffering and by seeking shelter behind the Wall he experienced less suffering.

3.4. Maria's Room: The Place. Maria, a woman in her early sixties, lost her husband due to prostate cancer. The time during his illness and death was very sad and trying and she was worn down. Still she felt that her husband was at ease with his dying. He had no pain and he did not suffer which helped her deal with the situation.

After his death she was still filled with sorrow but she said "I actually feel pretty good. The tears are still falling but it is OK. They are not done falling yet." The illness and death of her husband made her realize that life is short. "You cannot postpone life. You have to allow yourself to do things, to enjoy life. Life can be good and even though he is dead we had a good life together and that is something worth remembering. People might think that I do too many things now, but I believe that if he could see me he would be pleased that I participate in things." Maria could return to her and her husband's room. The room was a serene place to be in where she could be at peace after the death of her husband. She could remember the life they had together and confront the life that lay ahead. To be there was like entering a new life, a life without her husband. She missed him but life was still going on and she felt at peace with it. "You try to make the best of it, even though the worse possible has happened. There is no point in walking around being sad all the time. It can be dangerous to bury yourself in sorrow. To walk around and think about it the whole time only makes you go nuts. I do not think that I have to make the best of everything. I only think that it is like this, I cannot do anything about it." In the Place Maria felt like she belonged, it was home where she could reconcile with the past. She could also take a step outside her room and participate in the world.

4. Discussion

4.1. Methodological Considerations. The use of case study was a choice deriving from a desire to describe, explore, and understand how the next-of-kin in end-of-life care experience their situation and to explore the meaning of "the room" in these situations. This phenomenon is considered to be of interest to nursing, and the methodology provides opportunities for in-depth study of important characteristics of real-life events. According to Anthony and Jack [30], case study is a valid methodology that is justified and suitable for use in nursing science.

The use of deductive thematic analysis could suggest that the findings are solely based on our preunderstanding. It was therefore important for the trustworthiness of the study to challenge this preunderstanding. This was done by returning to Lassenius's [15, 16] descriptions of "the room" and discussing and comparing them with the findings from

the interviews in every aspect. Another way to accomplish this was to discuss the findings with another researcher. This external researcher was not involved in the study but familiar with Lassenius's work and therefore provided an outside perspective.

In the inductive analysis of the study, it was also important to acknowledge our preunderstanding so that it would not take over the interpretation in a way that did not leave room for the findings from the deductive analysis. The preunderstanding was tempered by maintaining a conscious and open-minded attitude towards the data material and analysis. Moreover, we had only a few expectations about the exact findings and instead adopted an attitude of openness and curiosity towards the experiences that were presented in the deductive analysis.

The aim of this study was to explore the meaning of "the room" as experienced by next-of-kin in end-of-life care and in doing so assess the possibilities of using Lassenius's [15, 16] research on the metaphors of "the room" as a way of understanding the suffering of the next-of-kin. One could question whether the results also are transferable to other caring situations where next-of-kin are involved. Transferability can be difficult to accomplish in qualitative studies, as the result must be seen and understood within the context in which the study has been carried out [30]. The readers must therefore determine themselves how far they can be confident in transferring the results of the study to other situations. The results of this study can be seen as abstract, but we have tried to present it in an accessible way. The presentations in four cases are easily transferred to caring situations in which the nurse meets next-of-kin in end-of-life care. This can contribute to further development of a care that is based on a holistic view which includes the next-of-kin. For the nurse to focus on the room at hand is one way to understand the complexity of being next-of-kin in end-of-life care. The thinking of room may therefore be a way to get in touch with the deeper and existential experiences of being next-of-kin in this trying situation.

In order to deepen the understanding of the room, further research is required to explore how the room is experienced in other caring contexts. It is also important to expand the perspective and seek not only next-of-kin's experiences but also the experiences of patients and health care personnel.

4.2. Discussion of the Results. The room is to be seen as a feature that is prominent in the world of the next-of-kin. The next-of-kin can however change to another room that is prominent in another moment. The room is therefore not static but dynamic.

According to Lassenius [15, 16, 20] the room is shaped by an ensemble of persons. They become the room. It shapes them to "be the room" in a true ontological sense. The findings of this study showed four dimensions of room as experienced by next-of-kin in end-of-life care. These were the Standby which can be seen as a *room of resting* from the suffering. The Asylum which can be seen as a *room of controlling* the suffering. The Wall which can be seen as a *room of hiding* from the suffering. The Place which can be seen as a *room of belonging*, allowing the person to

remember what has been and reflect on what lies ahead. These findings indicate four dimensions which seem to be mutually exclusive. It means that for Anna, Ben, Sam, and Maria the room represents the way of dealing with the trying life-situation. It is as a pattern that is prominent in their way of dealing with the suffering. According to previous research the experience of loneliness [2] and a longing for ground in a groundless world [3] is however a process of engaging in existential suffering. Furthermore Carlander et al. [32] have examined "my place in space" as an arena for identity work where daily life is organized, carried out, and negotiated. From this perspective, the findings of this study have a complexity that may be interpreted as man's struggle to establish a space to dwell in when life is too difficult to deal with (cf. [33]). Next-of-kin are seeking some kind of last resort that can carry them through the experience of being with their dying loved one. This is supported by Andersson et al. [5] who argue that experiences of limited freedom, worries and vulnerability, and conflicting emotions are part of an impending death. The complexity of the phenomenon may be understood in light of Lassenius [15, 16] who contends that man's existence is created in relation to others. The next-of-kin and their loved ones reflect the room they are in, which can be understood as an existential room, which is shaped by them.

In end-of-life care the nurse has to identify what room is prominent in the couple's relationship. Vulnerability and death as an impending threat [5] may cause the room to become a *Wall*, serving as a hiding place, as well as a room of resting that can release the burden of suffering. Presumably, a passage can be created between these two rooms that allow the room to transform into either shape. Roxberg [17] shows that an aspect of caring consolation is to keep the suffering at distance. It is a way to find rest, in and from the suffering. When next-of-kin in end-of-life care keeps suffering at a distance it alleviates the suffering. This is interpreted as a source of strength for the next-of-kin. The nurse's obligation is to assist the next-of-kin to find these rooms to hide in, respectively, to rest in and let him or her stay there as long as needed. More research about this process is required.

The control room seems to be locked and difficult to unlock (Ben's room). Caring becomes a matter of finding the right key to unlock the door. As Boucher et al. [9] and Linderholm and Friedrichsen [10] show, the ambition is to maintain control and to be present for the loved one. This is a positive ambition, but the control room in this study is more reminiscent of enduring as a state of suffering. The exposed persons, the next-of-kin, try to hold themselves as well as close relatives up by simply controlling the suffering. The enduring phase often serves as a way of surviving in order to manage responsibilities for others. This is a rational way of keeping the suffering at a distance in order not to fall apart [34]. This way of handling the suffering is met by being present and thereby creating an atmosphere of solace that reduces fear. The question is whether the control room is a room of fear, meaning that the next-of-kin is controlled by this fear. To endure suffering means holding oneself up but also letting oneself step over to emotional suffering. The latter is a state of suffering where the emotions are released

and control is reduced [32]. However, the state of suffering is emotionally very exhausting and sometimes the sufferer steps back to the state of enduring. For the nurse it is important to be sensitive to the next-of-kin's state, that is, which state they are in their suffering. This can be compared to Hebert et al. [13] thoughts about how preparedness can be seen in different dimensions; they suggest that the next-of-kin might need cognitive, affective, or/and behavioral support. Thus it is of uttermost importance not to force the next-of-kin into either state. Rather it is a matter of letting be and being there, as Lassenius [16] points out, to be room and give room for the individual person's unique way of expressing emotions in the trying situation of being next-of-kin in end-of-life care.

Finally, the room of belonging (Maria's room) is a serene room in which a peaceful homeliness and presence are prominent. In this room, the next-of-kin have an inner space where it is good to be. In this room, a peaceful togetherness is formed between the next-of-kin and the dying person. The nurse is invited to step into this togetherness by sharing the serenity of the room and the care can take place in a peaceful and loving atmosphere. Maria's room represents the process of suffering which according to Eriksson [35] means to accept the suffering. Maria has reached the end of the tunnel. The suffering is at ease and she can conclude what has been and open up for new life-possibilities. According to Eriksson [35] it is a matter of being in the suffering and becoming out of that suffering. Maria is not the same person as before her husband got ill. Her room reflects a kind of wisdom that comes with having been in a struggle with the suffering that made it possible to enter a new dimension of life, to become out of suffering.

5. Conclusion

The findings of this study reflect such a life-situation where hope and despair encounter each other and where rays of hope enlighten a way to a possible future (cf. [15, 16]). The results explain and may well assist nurses to understand the experiences of being next-of-kin in end-of-life care as forming a room of rest from the suffering, a room of controlling the suffering, a room of hiding from the suffering, and a room of belonging.

Conflict of Interests

The authors declare that there is no conflict of interests regarding the publication of this paper.

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