



## Getting to Know Patients' Lived Space

by Annelise Norlyk, Bente Martinsen and Karin Dahlberg

### Abstract

*The present paper explores patients' experience of lived space at the hospital and at home. To expand the understanding of the existential meaning of lived space the study revisited two empirical studies and a study of a meta-synthesis on health and caring. Phenomenological philosophy was chosen as a theoretical framework for an excursive analysis. The paper demonstrates that existential dimensions of lived space at the hospital and at home differ significantly. For the patients, the hospital space means alien territory as opposed to the familiar territory of home. To some extent the experienced differences are due to the physical environment; however, as our analysis shows, other and more significant meanings are also involved. For patients, lived space at the hospital primarily concerns the influence of complex institutional power structures and specific cultural and social conventions, e.g. the role of the good patient and the ambiance of hospitals. Home, on the other hand, offers familiar lived space in which patients feel protected and safe. Further, the paper relates patients' experience of lived space to a phenomenological view of lived space in order to illustrate the radical influence of illness on patients' lifeworld and experience of lived space. The combination of illness and general discomfort may influence patients' experience of home negatively; the former experience of home as a sanctuary changes into feelings of being left on one's own and burdened by too much responsibility. Consequently, in the light of the increasing focus on patients' self-monitoring at home, it is important for healthcare professionals to recognize the influence of spatial aspects on patients' well-being both at the hospital and at home.*

This article presents new insights regarding the existential nature of patients' lived space at the hospital and at home. Lived space refers to 'the more' of the physical space, in other words, the felt, experiential space. The hospital setting can be the source of such a lived space, being a place with a specific atmosphere and a specific logic that has an influence on how people feel, act and behave. Although the hospital setting is meant for patients, it is mainly a common place for health professionals but patients may feel "out of place" (Paterson, 1988, p. 35). Thus, although they may be in the same room, professionals can feel at home while the patient does not feel at home. In contrast to the hospital setting, patients at home are in their habitual environment, in a space that is familiar and meaningful. However,

when illness and professional care invade patients' homes, the experience of home as a lived space might change.

According to Merleau-Ponty (2005), lived space is an existential theme that refers to the world in which human beings move. However, even though human beings live their everyday lives in space, they do not necessarily reflect upon space. Lived space can go unnoticed but at the same time can influence the experience of well-being. This is also true of the experience of well-being as a patient.

The aim of this paper is to expand our understanding of the existential meaning of lived space as it appears for patients. Such insights can help health care

professionals to better understand how patients perceive their caring context and the sometimes ambiguous experiences of lived space. In order to achieve this aim the paper revisited two empirical phenomenological studies as well as a meta-synthesis of caring science research. Phenomenological philosophy was chosen as the theoretical framework of the new analysis.

## Background

As early as the 1850s Florence Nightingale stressed the importance of the environment for health and well-being. Nightingale saw the locus of healing within people themselves and stated that the art of nursing is to optimize a healing environment in which patients are offered the best possible conditions in order to allow 'nature' to act upon them (Nightingale 1859/1969). Since then, several other health care theorists have investigated the interaction between human beings and their environment. In the 1970s and 1980s, theorists such as Martha Rogers (1970) and Jean Watson (1985) worked intensively with humans' interactions with their environment. These theorists believed that health and well-being can be improved by supportive surroundings in which healing conditions are optimal. Likewise, Jacqueline Fawcett (2005) described 'environment' as one of four central concepts that make up the meta-paradigm of nursing, together with person, health, and nursing. She further stated that 'environment' is possibly the least explored and understood of these concepts.

Our search in the literature shows that the influence of environment on patients' well-being has been discussed in various empirical studies where the authors argue that the healing process is influenced by the physical environment (e.g. La Torre, 2006; Lorenz, 2007; Ulrich, 1984) and by the atmosphere of the ward (e.g. Edvardsson, Sandman, & Rasmussen, 2005; Rasmussen & Edvardsson, 2007; Wilde, Starrin, Larsson, & Larsson, 1993). The design of the sickroom itself can be a source of stress for patients and staff, but it can also be an environment that promotes healing (La Torre 2006; Lorenz, 2007). Light, sound, and views of green outdoor areas also have a positive impact on patients' experiences of pain and stress. These factors also influence the length of admission and can support the healing process of patients (Frandsen et al., 2009; Lawson, 2010; Ulrich, 1984). For instance, post-surgical patients recovering in a room looking out on a natural scene tend to recover faster than do patients in rooms that face a brick wall (Ulrich, 1984). Likewise, decreased noise may significantly affect patient outcomes (Lorenz, 2007). Consequently, healing architecture and a new evidence-based design approach are now becoming established within the

health care sector in order to improve the patients' hospital stay (Lawson, 2010).

Edvardsson et al. (2005) provided an overview of research describing the influence of the environment on patients' well-being and experiences of nursing care. They found that both the physical environment and the psychosocial ward environment play important roles in reducing patients' suffering. Rasmussen and Edvardsson (2007) used the concepts of 'atmosphere' and 'at-homeness' to describe phenomena they identified in several empirical studies as being central for the well-being of patients in institutional settings. Through these studies, the authors concluded that nursing care and the psychosocial and physical environment are inseparable entities. The authors found these inseparable entities hard to describe precisely and suggested that they interact as "the atmosphere of a place" (Rasmussen & Edvardsson, 2007, p. 119). The nature of this atmosphere may be understood in terms of lived space.

Hall and Brichmann (2009) found that mothers of preterm infants experienced the different kinds of rooms in the unit as having their own unique physical, cultural and existential meaning. One room could be experienced as "the quiet caring room" while another was described as "the hustled passage room" (p. 131). The tone in the rooms and the ability to create a personal space meant a lot to the mothers' feeling of being cared for. These findings are in accordance with findings reported by Martinsen (2006) who pointed out that the sickroom is a special space with its own resonance and dignity, which are transferred to patients.

The studies described above provide important insight into the complex relations between patients and their environment. However, despite the existence of these studies little is known about the existential nature of patients' experience of the environment as a lived space. Our earlier empirical phenomenological studies focusing on patients' experiences support the view that the psychosocial and physical environments are inseparable entities that can be articulated as the experience of an atmosphere (Martinsen, Harder, & Biering-Sorensen, 2008; Martinsen & Norlyk, 2012; Norlyk & Harder, 2009, 2011). During our studies it became clear to us that this experience of atmosphere was of an existential nature, a lived space, which deserved further analysis.

## The empirical foundation

The empirical basis for this paper was developed from phenomenological studies of patients' lived experiences (Martinsen et al., 2008; Martinsen &

Norlyk, 2012; Norlyk & Harder, 2009, 2011) and from a meta-synthesis of caring science research (Dahlberg & Segesten, 2010). All studies were conducted within the framework of Reflective Lifeworld Research (RLR; Dahlberg, Dahlberg & Nyström, 2008). RLR is characterized by a phenomenological approach which builds on an interest in the lifeworld and phenomenological epistemology. Researching openness is emphasized in terms of 'bridling', which means to slow down the process of understanding. Bridling demands from researchers a reflective and critical attitude in order to see the phenomenon in a new way. According to the RLR framework, understanding a phenomenon such as patients' experiences of health and care during interviews and observations, is a matter of dwelling and being sensitive to the impressions that move the researcher, without taking anything for granted and without believing that what one perceives is actually the reality.

### ***Study one - patients' experience of participating in a fast-track programme***

The aim of this study was to explore patients' lived experience of participating in a fast-track programme after colonic cancer surgery (Norlyk & Harder, 2009, 2011). Fast-track programmes are evidence-based plans for care and treatment aiming to accelerate postoperative recovery. These programmes include a standardized daily nursing care regimen focusing specifically on evidence-based goals for nutrition, mobilization, and a plan for discharge two to three days post-surgery. The patients are explicitly expected to participate actively in meeting the appointed goals. The patients are also expected to continue to follow the principles of the regimen after discharge.

A total of 16 patients with colonic cancer, aged between 53 and 77 years, were interviewed two weeks and two months after discharge. The interview process was open but focused on the phenomenon of participating in a fast-track programme. The patients were asked to describe how they had experienced the post-operative period and how they had experienced participating in the fast-track programme at the hospital and at home. The patients were encouraged to describe and elaborate on specific situations. For example, patients were asked: "What was it like for you to get out of bed the first time after surgery?" and "How was your first day after discharge?"

A descriptive phenomenological analysis revealed two essential structures, labelled 'the lived experience of participating in a fast-track programme during hospitalisation' and 'the lived experience of participating in a fast-track programme after discharge'. Within both structures, participating in the

programme involves the patients' ability to overcome dilemmas related to discomfort and illustrates the need for support from both professionals and relatives in order for patients to gain the necessary strength and courage, as well as the will to comply with the recommendations of the daily regimen. The differences between the two structures are related to experiences of the lived space at home and the lived space at the hospital. Participating in the fast-track programme at the hospital is intertwined with complex power structures that can place pressure on the patients. These power structures are related to the programme, the hospital norms, and the role of being a good, cooperative patient. After discharge, however, the patients experience a change of role from being the good cooperative patient to being in charge. Thus, the findings show that lived space plays a crucial role in the patients' recovery process and their being-in-the-world (Norlyk & Harder, 2009, 2011)

### ***Study two - patients' experiences of assisted feeding***

This study consisted of two perspectives on the phenomenon of assisted feeding. The first part of the study was an exploration of the experiences of people living with high cervical spinal cord injury in their own homes with 24-hour personal assistance. In this study, 16 patients were interviewed twice within a period of 18 months (Martinsen et al., 2008). The second part of the study was conducted in two neurological wards among people with language impairment (Martinsen & Norlyk, 2012). A total of 42 incidents of assisted feeding were observed. Field notes were taken simultaneously and a few simple questions were posed to the caregivers and the patients.

The exploration of assisted feeding among people living in their own home found that the construction of a new eating pattern based on help from another human takes place on two levels. One level consists of an unchanging pattern repeated meal after meal, whereas the other level is temporary and sensitive to the context. In this part of the study, where participants did not have to consider any institutional structures, assisted feeding seems to be conducted more freely, without having to consider the gaze of strangers.

Analysis of the observations in two wards showed that assisted feeding is a transaction characterized by efficiency when performed in a hospital setting. Caregivers tend to work under such time-pressure and with such goal-oriented determination that the sense of joy normally connected to eating is threatened. Also, patients receive help where it seems convenient for the caregivers, for instance in the corridor, apparently without considering how the surroundings influence patients' inclination to eat.

Both parts of the study of assisted feeding found that the patients' spatial experiences play a significant role. Assisted feeding is identified as a vulnerable situation where a person receives help with an activity normally considered to be an adult's private domain. Although the assistance clearly differs in these two contexts, which determines how assisted feeding is conducted, the study also found that patients with a need for assisted feeding do not want to attract any unnecessary attention either inside the hospital or outside.

### **Study three - a meta-synthesis**

This study concerned a meta-synthesis of caring science research that has generated a theory of health and caring (Dahlberg & Segesten, 2010). The meta-synthesis included 74 publications, of which 26 were PhD dissertations that described more than one study. The studies came from a wide range of caring contexts. Patients and their relatives as well as professional carers were included. The findings displayed descriptions of health as the goal of caring. Health was defined as an experience of well-being together with a capacity of 'being able to', which related to the individual's major as well as minor life-projects. The synthesis also displayed lived space and lived time as essential aspects of the caring context. These aspects were also connected to the experience of existential vitality, existential meaning and belongingness, and a sense of life rhythm.

Although these primary studies had different purposes and different foci from the present study, the findings of all three studies indicated that spatial aspects play an important role for patients. Based on these studies we were inspired to further investigate and analyze the concept of lived space.

### **Theoretical framework**

Phenomenological philosophy was used as a theoretical framework because this perspective is able to expand the understanding of patients' lived space as it appeared in the previous research studies. In particular, the lifeworld theory was used because it includes themes of intentionality, temporality and spatiality.

The phenomenological tradition beginning with Husserl provides a conceptual framework in which the lifeworld of human beings takes a central place. Husserl (1984) described the lifeworld as an immanent and transcendent 'world' in which every "life-praxis is engaged" (p. 121). Accordingly, the lifeworld refers to our everyday existence in and through which we live our lives. The lifeworld is an intuited, common, subjective, intersubjective and pre-given world characterized by what Husserl (1984) called the natural attitude, in which the world around

us is perceived without reflection. Thus, the world "is pre-given to us all quite naturally, as persons within the horizon of our fellow men, i.e., in every actual connection with others, as 'the' world is common to us all" (Husserl, 1984, p. 122). Stated simply, the lifeworld forms the foundation of understanding humans, our lives, health, suffering, and well-being. It therefore follows that humans (for example, patients) can never be fully understood without taking their lifeworld into account.

Crucial dimensions of the lifeworld, such as temporality, spatiality, intersubjectivity, embodiment and mood, have been described and referred to as the constituents of the lifeworld by Husserl (1984), Merleau-Ponty (2005) and other phenomenologists (e.g. Ashworth, 2003; Todres, Galvin, & Dahlberg, 2007). Lived space is closely interrelated with lived time. Husserl (1984) stated that "the world is a spatiotemporal world; spatiotemporality (as living, not as logicomathematical) belongs to its own ontic meaning as lifeworld" (p. 168). Accordingly, lived space is not a measurable mathematical space but an existential theme that refers us to the world or settings in which we move.

Merleau-Ponty (2005) further underlined that our existence is embedded in both time and space: "the experience of our body teaches us to embed space in existence. To be a body, is to be tied to a certain world (...) our body is not primarily in space: it is of it" (p. 171). In other words, the space in which we find ourselves affects the way we feel; it is possible to say that we become the space we are in and the space becomes us. According to Todres et al. (2007), lived space refers to the encounter with an enviroing world; a world of places, things and situations that have meaning for living, and consequently for health. Things in our world have a number of potential meanings depending on where they fit into our lives, whether they are momentary and/or long term.

Bollnow (1967) also elaborated on lived space. Like Merleau-Ponty (2005), he argued that lived space is a felt space, that it is experienced in terms of large or small, empty or crowded, above or below, far or near, across, and through all locomotor abilities. Bollnow (1967) distinguished between inner and outer space. Home refers to an inner space and is an area of security and peace. Home is a space in which we are protected, hidden, and safe; it is space that is familiar, and a space into which we can withdraw and be ourselves. Outer space is the space of danger and refers to strangeness, distance, and to endless, wide-open space (Bollnow, 1967).

### **Ethical considerations**

Ethical approval was not required for this paper, but was obtained for previously published research.

## Analysis

In order to revisit data from previously published research we made use of RLR. This means that the analysis focused on describing the world as experienced and searching for a meaning structure that essentially describes the phenomenon of interest. We returned to the original empirical texts with a meaning expanding focus. Using a phenomenological framework we wanted to see something more and new in the descriptions of patients' existential meanings of lived space.

During the analysis process, we asked questions such as: What is the patients' experience of lived space at the hospital and at home? What is the relationship between lived space and health? What is the relationship between lived space and illness? What is the relationship between the atmosphere of rooms and lived space? The analysis also moved back and forth between the data and the emerging meanings in order to validate the findings by reaching a consensus regarding what constituted the patients' existential meaning of lived space. As in all RLR guided research, attention was paid to the question of bridling (Dahlberg et al., 2008), which involves adopting a reflective stance to the whole process of understanding in order to avoid understanding too quickly and thus taking emerging meanings for granted. Bridling further involves a reflective stance that helps the researcher to avoid allowing pre-understanding to affect the analysis in an uncontrolled way. This second aspect of bridling was of particular importance in this analysis due to the previously conducted analyses as well as the import of external data relating to the philosophical understanding of the phenomenon. Bridling is a way of being careful in analysis and not allowing the strength of theoretical data to silence the soft voice of the lifeworld.

The aim of this study was to describe a structure of the meaning of lived space as experienced by patients, including essential themes as well as empirical particularities and nuances, referred to as constituents.

### Excursive findings of lived space

The data showed rich variation and the experiences of space differed within the data. To some extent, the experienced differences were clearly due to the physical environment. However, the excursive analysis suggested that there were also other and more significant meanings involved. To the patients, the institutional structures as well as the specific cultural and social conventions associated with the hospital space gave an unfamiliar dimension to this space. In contrast, the patients' home essentially refers to space that represents feelings of belongingness and tranquility as well as close

personal relationships. Accordingly, the hospital setting and the patient's home can be seen as two different types of lived spaces in which patients move and employ their health processes.

The findings show that for the patients the hospital space was alien territory. The lived space at the hospital primarily concerned the influence of complex power structures and social conventions, which included the role of the good patient, and the influence of the atmosphere of the rooms. Home, on the other hand, offered lived space in which they felt protected, hidden, and safe. It is a space that is familiar and where they can withdraw and be themselves. While the findings primarily refer to these positive connotations of patients' homes, specifically in relation to lived hospital space, they also show that the lived space at home can hold negative aspects that should not be ignored. Patients' spatial experiences, although originally of a familiar and kind form, were changed by the illness and patients can be overwhelmed by discomfort and insecurity when at home.

This essential theme concerning patients' lived space at the hospital was labelled 'The hospital - a world of its own'. This essential theme was further elaborated through two interrelated constituents: 'A shared space that lacks peace and quiet' and 'a space with many brief interactions'. The essential theme covering patients' lived space at home was labelled 'Home - my own world', and was further elaborated through the use of two interrelated constituents: 'A personal space' and 'a space of protection'. These themes are discussed below. Quotes from the original studies are provided as examples of explicated meanings.

#### *The hospital – A world of its own*

The hospital setting seems to have its own modality of spatial meanings. It is like a world of its own that the patients cannot influence. Lived space at the hospital is characterized by a specific logic and atmosphere. In this space, there is a complex and potentially intimidating web of power. The power structures are related to the institutional structures, the hospital norms and the interactions with the professionals.

The intertwined structures put pressure on the patients. In the hospital, space is a specific set of implicit expectations related to expected behaviour. This set of expectations is powerful and dictates behaviours from which the patients find it difficult to escape. The patients adapt to the professionals' expectations and, if needed, they push themselves to cooperate. The patients incorporate the rules and principles and, as a consequence, expect a lot of

themselves. In this regard, one patient stated: "If they set up a programme, then one should abide by it".

The lived space at the hospital has its own norms and its own script, which implicitly define the patient's role as that of the good, cooperative patient. Patients' experiences of the hospital space were described by using different metaphors and analogies; for example, "It is like being a very small fish in a big pond" or "it's like a soldier's life, living in barracks, there is nowhere to go, you are obliged to live with the ways things are, and you can't do anything about it". In a similar manner to these places, the hospital occupies and almost absorbs the lifeworld.

Although the tone of voice used by professionals can be pleasant and humorous and signal equality between patients and professionals, it can also be authoritarian and underline an asymmetric power relation and lack of respect and dignity. Likewise, in this space ordinary social conventions might be overridden by norms different from the norms of everyday life. For example, patients who need assisted feeding might be given one or more pills with a mouthful of food without being informed. One participant commented: "Ugh, there was a pill in my ice cream". In other cases, caregivers could sneak some food or liquid into the patient's mouth as a means to wake a sleeping patient in order to promote cooperation during the assisted feeding. In one study on forensic psychiatric care included in the meta-synthesis, a patient noticed two professional carers playing cards together. When he asked if he could participate he was told to go to his room instead.

Our findings show that patients experience the physical environment and the atmosphere of this environment as a space filled with meaning. This is in accordance with Merleau-Ponty, who rejected a clear distinction between the experienced space and the physical world. As Merleau-Ponty (2005) stated, "Our relationship to space is not that of a pure disembodied subject to a distant object but rather that of a being which dwells in space relating to its natural habitat" (p. 55). The experiences of things such as physical rooms, explicit and implicit rules, professionals' behaviour as well as their voices, are all intertwined and together they characterize the experience of being a patient in a hospital.

#### ***A shared space that lacks peace, quiet and privacy***

The hospital was described by the patients as a noisy space, with hectic activity both day and night. It was further described as a place that lacks any form of complete personal space. The sickroom and the units are both spaces that the patients share with other people. The experience of being in this busy atmosphere and the constant, high level of activity can be stressful. For example, meals have to be

conducted within a specific time-frame in competition with other important activities as well as influenced by noise from devices such as bells, telephones, and televisions. Patients stated that even their sleep is affected by various activities. Being in this space is described by patients as being "at a major railway station".

Our findings also demonstrate that the physical environment significantly influences patients' well-being. Patients who stayed in shared rooms with several beds described the sickroom as a small and crowded place with no privacy and with undesired sounds, sights and smells. To be in this shared space could mean that the patients have to face sickrooms as well as corridors as foul-smelling spaces, for example the smell of flatus in the sickroom as illustrated in the following quote: "I was in a six-bed room and the noises and smells could be nauseating". Patients could also overhear professionals conversing about urine and faeces during meals. Fellow patients could also have bowel movements in the sickroom while the meal took place.

Although the professionals tried to create a degree of privacy for the patients by drawing curtains around the beds, patients experienced this as a mere illusion of privacy. Curtains are not walls, and the patients could hear or in other ways sense what was going on in the next bed. Also, as one patient described it, "this constant drawing back and forth of curtains was noisy and stressful".

All of these experiences (the noise, the smells, the lack of privacy and having to share bathrooms and a potentially soiled toilet) gave rise to feelings of being in a space with a low degree of individual dignity and a low degree of authority.

#### ***A space with many interactions***

For patients, a hospital is a place where they have a series of close, but usually brief, interactions with different professionals and with fellow patients. The findings show how patients link the space of the hospital to feelings of security because of the ready access to professional help. Patients also experience the professionals as creating an atmosphere in which the patients feel supported and cared for. Although the interaction was brief, a patient reported how this interaction supported him: "When they came and said I was to get out of bed, I thought, my goodness, I don't dare, but it really went well. They showed me how to lie on my side and then roll over. It really was very easy and not unpleasant at all."

Despite the existence of many interactions, patients could also experience comfortable or intimate spaces at the hospital. For example, outpatient clinics at the hospital were described as places that display

closeness in the relationship with the professionals. In particular, such descriptions came from patients who had experienced ambulatory care. The patients described how in these spaces they felt that they were the center of attention, which was different from the experience in the hospital ward. "In the ambulatory clinic, you feel that you are the only one and then, when you get back to the hospital ward, there is a whole lot of people, coming and going both night and day."

The findings also illustrate that despite being constantly surrounded by many people, patients also experienced the space of the hospital as a place in which they felt lonely, on their own and even deserted. For instance, patients described how they feared having been forgotten by the professionals, despite having expressed their health problems, such as urination troubles. The experience of loneliness, which was further explicated in the meta-analysis, is clearly connected to a sense of belongingness and not to the number of people by whom one is surrounded. In particular, a place that is meant to be supportive of health but that fails to offer a warm and welcoming atmosphere induces loneliness and suffering as a result of the type of care offered. Such experiences of closeness and distance in the relationships with the professionals also include patients' experiences of dialogue with the professionals. There is an explicit wish to engage in dialogues with professionals, and when dialogues become more sporadic then patients are left with a feeling of being abandoned.

### ***Home – My own world***

Home represents a safe haven or a sanctuary for the patients. Although patients may struggle after discharge, they also describe how coming home can have healing effects. Unlike the hospital, home is experienced as quiet and peaceful, although sometimes it is too quiet.

Home is primarily a lived space in which the patient is the person in charge. When at home patients follow their own rules and own values based on their personal frame of reference. Hence, lived space at home is characterized by feelings of belonging and tranquility, and of close personal relationships that can offer support and care. These feelings are expressed as deep and extremely important for patients. One patient went as far as to state: "I actually cried with joy on returning home after discharge".

An essential aspect of patients' experiences is that illness changes their lives in more or less significant ways. The disruption of a patient's normal body functions also means a disruption of smooth and well-functioning access to the world. Illness means that

previously silent aspects of the patient's lifeworld become obvious and must be reflected upon. Patients have to consider the limits of their body, which entails a continuous re-organization of everyday routines. The patients need to modify or perhaps set aside their former everyday actions. Ordinary activities like washing the stairs or mowing the lawn can suddenly be experienced as challenging or even impossible. The illness has thus not only caused a breakdown of ability but also a concurrent existential disruption of the patients' relationship to their lifeworld and a restriction of lived space. One patient described this as follows: "In the beginning my world diminished into next to nothing, but now it has started to expand again."

### ***Home as a personal space***

For patients the lived space of their homes is a personal space that has its own patterns. For example, the patients described how things such as sleeping in their own beds and having their own familiar belongings have an important healing influence. At home patients can establish a daily rhythm and professional recommendations can be reinterpreted and included in the daily routines to the extent to which they fit into the individual patient's lifeworld and everyday situation. One patient described it as follows: "At home I can be myself."

Thus, in such personal space patients change their role from complying and adapting to taking over and taking charge. Professional recommendations are adjusted based on the patients' own framework of understanding, usually with no deeper knowledge of the physiology or the rationale behind the professionals' advice. For example, one patient stated: "I decided to throw out the painkillers (...) I think that the pills prolong the process. So, it was a question of pulling yourself together and get through it."

In this personal space at home, the patients also adhere to their own principles. For example, patients who needed assisted feeding could emphasize the relational aspect of the meal by choosing to eat together with the personal assistants, relatives or visitors. At the hospital, there were no traditions for dining with people other than fellow patients. One patient stated: "I think it is cozy when we all sit around a table and dine together."

### ***A space of protection***

Although the patients described how professional interaction help promote strength to cope with the altered life situation they also stated that they need a private zone in which they can find peace and solitude. At home, they are able to create a private place to which they can safely retire: "I really need to be alone sometimes, and I feel very privileged,

because at home I have a room of my own and I can close the door". There are experiences of familiarity and security when moving around in one's home, where rooms are recognizable and well-known. For example, one participant described the feeling of security he/she gained from relaxing in their favourite chair.

Familiarity is related to experiences of protection and intimacy. For example, receiving meal assistance in public places such as a restaurant requires considerable adaptation to the interest of fellow human beings. In their own home patients are protected from the gaze of unknown people and they alone can decide the structures for their meals. In their own home and in the absence of strangers, patients tend to use devices, such as straws and bibs, that they do not use outside their home. The patients also reported that in this space meals are not interrupted by activities like telephones, fellow patients, rounds and other incidents like they are at the hospital.

However, patients also described how illness infuses them with a sense of vulnerability which influences their whole existence and can have a negative effect on their experience of home as a sanctuary. Moments of escalating insecurity could arise. Unaccustomed bodily discomfort, unfamiliar sensations and even new insights in the weakness of a body that fails, could change the experience of home as a space of protection into feelings of uncertainty and aloneness despite the presence of relatives. This may result in a deadlock, leaving the patients with feelings of powerless or feelings of being left alone with too much responsibility:

I was in pain and was uncomfortable ... was in and out of bed, and then back to the toilet to try again. I was afraid to press too much ... that is my insecurity again ... will it be alright? (...) my wife was very calm for a while, and then she also started to get worried as I was really poorly. Things turn into a vicious circle ... and then we both cried.

Based on the characteristics of lived space found in this study in the next section we relate the excursive findings of the phenomenon in both contexts to general phenomenological perspectives on lived space.

### Phenomenological perspectives on lived space

Our findings concur with those of van den Berg (1972), Gadamer (1993/1989), Toombs (1993) and Dahlberg and Segesten (2010) in suggesting that illness has the power to radically change an individual's lifeworld and that the experience of lived

space in illness changes significantly. Toombs (1993), herself suffering from multiple sclerosis, stated that the range of possible actions becomes severely circumscribed during illness and physical space itself takes on a restrictive character. Also, in illness other people and the outside world recede into the distance (van den Berg, 1972). Recognizing that physical space represents functional space, Merleau-Ponty (2005) noted that it is through bodily actions and movements that the embodied individual "inhabits space" (p. 117). Consequently, illness itself means a disruption of lived space in which functional space assumes a problematic nature.

The present analysis shows that illness causes a constriction in the lived space of the patients, which engenders a heightened sense of distance between the patients and their surroundings. For example, the distance to the bathroom was experienced differently before and after surgery. Similarly, patients who needed assisted feeding felt uncomfortable when eating in public places and preferred to eat at home immediately after their injury. Also, one of the studies in the meta-analysis focused on patients with Alzheimer dementia and found that the former well-known home became a strange and even dangerous place. One of them described how the former beloved garden now was a place that he was too scared to visit and that he consequently stayed indoors. This illness-related change in the patients' everyday world and their functional space means that they, in varying degrees, perceive distinct change in the spatiality of their bodies. The illness does not need to be severe for the change to happen. Toombs (1993) reminded us that although the severity of the illness is related to, and judged by, the extent to which the patient's lifeworld is disrupted, even a simple cold produces a concurrent disruption of an individual's being-in-the-world.

Our findings also show that after a period of constriction the patients' spatial world may gradually expand over time and increasingly include what Bollnow (1967) referred to as "the outer space" (p. 182), that is, the space outside the protective boundaries of the home which denotes breadth, strangeness, and distance. For the colonic patients the expansion of their spatial world was related to the progression of their recovery whereas for patients with spinal cord injuries the expansion was related to the adaptation to their physical environment. Only gradually did they expand their comfort zone when eating. The expansion of lived space, together with the process of recovering, is related to the individuals' sense of belongingness and meaningfulness in their lived context as well as to their experience of existential vitality and life-rhythm (Dahlberg & Segesten, 2010).



The lived space at the hospital is more complicated. It is characterized by a sense of strangeness and discomfort and not belonging. According to Bollnow (1967), strangeness is an area in which man no longer knows his way around and where he therefore feels helpless. The feeling of strangeness can overpower man and may result in feelings of inexpressible homesickness (Bollnow, 1967). In general, patients experience their home as a space that represents a safe haven or a sanctuary, and as such home is an attractive option, despite the potential discomfort and insecurity. In contrast to the hospital, the resonance of home is characterized by dignity and signals well-being. According to Heidegger (2001), home is related to the fundamental sense of our being and thus has an almost sacred character. For Heidegger (2001), home is the lived space that is uncovered, significant and meaningful. The old German word for building, *buan*, means to dwell, which signifies to remain, or to stay in a place. Home is a personalized space where we feel that we belong (Heidegger, 2001). Our findings show that this feeling of belonging is significant for patients. However, in order to feel at home in this existential meaning, illness must not be overwhelming. For example, patients may need to rearrange the home in order for it to be well-functioning and therefore able to offer well-being. Consequently, a hospital can also offer experiences of existential home where patients can dwell and stay in comfortable peace in a space where their health processes might be supported and strengthened. Such lived space, however, demands radical adjustments in architecture as well as in caring approaches (cf. Dahlberg & Segesten, 2010).

### Closing reflections

The findings show that lived space contains both physical and existential aspects that significantly influence patients' well-being. Hence, the findings support existing knowledge that suggests that the physical environment is central for the well-being of patients (Frandsen et al., 2009; La Torre, 2006; Lawson, 2010). They also support the importance of decreasing noise, the creation of a personal space, a positive tone and atmosphere in the sickroom (Edvardsson et al. 2005; Hall & Brinkmann, 2009; Martinsen, 2006; Rasmussen & Edvardsson, 2007).

The present study contributes to current understandings by illustrating that existential dimensions of lived space influence patients' health in terms of well-being and the experience of 'being able to'. Further, this study found that the relationship between illness and lived space should not be underestimated. The findings of the present study acknowledge the importance of creating a sense of 'home space' even in hospitals and may help alert health professionals to the complexity of power structures in hospitals. It

may also help health professionals recognize the impact on the individual patient. It must also be recognized that hospitalized patients are affected negatively by lack of peace and quiet and lack of personal space, and this makes it difficult for patients to uphold their dignity and privacy as well as a health promoting life-rhythm (cf. Dahlberg & Segesten, 2010).

Several empirical studies have elaborated on aspects that describe the meaning of home. These aspects embrace themes which contain positive connotations such as ownership, responsibility, control, privacy, refuge, togetherness, safety, rootedness, harmony, joy, power, and freedom (Després, 1991; Mallett, 2004; Moore, 2000; Roush & Cox, 2000; Rydeman, 2013; Sixsmith, 1986; Zingmark, 1995). Our study contributes to existing knowledge by showing that these positive spatial experiences of home may change during illness. Our findings clearly show that patients are also vulnerable at home. Patients' spatial world might change suddenly and unexpectedly. Home can become unmanageable and unfriendly, a place in which patients feel alone and unseen. Patients may consequently feel unnoticed by professionals or other people who are meant to be supportive. The combination of illness and general discomfort can have a negative effect on patients' experience of home as a sanctuary and could lead to feelings of being left with too much responsibility. Therefore, the meaning of home among people suffering from illness may be an ambivalent experience and is different from the meaning of home among healthy people. This is an important point due to the increasing focus on patients' self-monitoring at home. Consequently, the importance of lived space in health care cannot be underestimated.

### Implications for practice

With reference to Gadamer's hermeneutic circle, the idea of the utility of findings in RLR is understood as an on-going process of understanding the way in which the findings are put in play, provoked and used in new contexts in order to release new meanings (Dahlberg et al., 2008). Discussing the utility of qualitative research findings, Todres (2008) argued that by paying attention to the evocative power of qualitative research findings, these can become a rich resource for sensitizing practitioners to engaging in the complexities of practice. Following Todres (2008) and Dahlberg et al. (2008), the insights into patients' existential dimensions of lived space can inform, guide, and encourage health care professionals to reflect on the aspects presented in this paper. These areas especially concern the need for health care professionals to pay more attention to the individual patient's lifeworld and to recognize the influence of lifeworld on the individual patient's health processes.

In clinical practice this means that professionals need to expand their focus from simply providing treatment and factual information to also including a more lifeworld oriented and relational approach. Hence, to promote lifeworld-led care it is important that health care professionals are aware of how spatial aspects

play an important role in patients' health and well-being and provide a sense of 'being able to' both at the hospital and at home.

### Referencing Format

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### About the Authors



Annelise Norlyk, PhD, is an Assistant Professor in Nursing Science, Department of Public Health at Aarhus University, Denmark. Her research focuses on patients' and relatives' experiences of the transition from a brief period of hospitalization post-surgery to a lengthy recovery period at home. Her expertise concerns patients' and relatives' experiences of early discharge, self-care, participation in fast-track colonic surgery programmes and how patients cope with the loss of a leg. She also has a passion for methodology and her particular interests are phenomenology and hermeneutics. Her work is informed by phenomenological research approaches and resulting methodological implications.

E-mail address: [an@sygeplejevid.au.dk](mailto:an@sygeplejevid.au.dk)



Bente Martinsen, PhD, is an Assistant Professor at Aarhus University, Denmark. Her research is concerned with peoples' experiences of physical dependency with a special focus on the phenomenon of assisted feeding. She has investigated this phenomenon among people in their own homes as well as among patients admitted to hospital. Martinsen has studied caregivers' experiences of assisting people with feeding in a hospital context. Methodologically, her particular interests are phenomenology and hermeneutics. Her work is informed by phenomenological research approaches and the resulting methodological implications.

E-mail address: [BM@sygeplejevid.au.dk](mailto:BM@sygeplejevid.au.dk)



Karin Dahlberg is Professor in Caring Science, and is at present Guest Professor at Linnaeus University, School of Health and Caring Sciences, Centre for Lifeworld Research, and at University of Gothenburg, Centre for Person-Centred Care, Sweden. She has a particular interest in continental philosophy and phenomenology, and how these ideas can strengthen the knowledge base of health care. For many years she has given lectures on phenomenological research in Europe, the US and Asia. With the publication of a new theory of health and caring, her lecture base has widened. She is presently working on two new books, one on research methodology for beginners, and one on health and caring science.

E-mail address: [karin.dahlberg@pajebogard.se](mailto:karin.dahlberg@pajebogard.se)

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