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**Being in transit and in transition.
The experience of time at the place, when living with severe
incurable disease - a phenomenological study**

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BEING IN TRANSIT AND IN TRANSITION

The experience of time at the place, when living with severe incurable disease - a phenomenological study

The aim of this study is to describe the experience of time as it presents itself at the place being situated when living with severe incurable disease and receiving palliative care. The empirical data consist of 26 open-ended interviews with 23 patients receiving palliative care at home, at a palliative day care; in a palliative bed unite in hospital or in a nursing home in Norway. A common meaning of a shifting space for living emerged from the analysis and was revealed through three different aspects: (i) *Transition from a predictable to an unpredictable time*: To live with severe incurable disease marks a transition to a changed life involving an ongoing weakened and altered body with bothersome symptoms making experience of time different and unpredictable. (ii) *Transition between a safe and unsafe time*: When time is unpredictable, feeling safe is revealed as essential to how time is experienced at the place being situated. (iii) *To be in transition from a homely to a homeless existence*. In a time of increased bodily weakness, unpredictable ailments and displacements the sense of belonging to the place is revealed as significant to the experience of time. Not knowing where to be in a time of change is like an existential cry of distress where the foothold in existence is lost. The findings are discussed and interpreted as an embodied experience originating from the passage of time continually affecting life sometimes so fundamentally that it marks a transition to a changed space of life that is reflected in the experience of time.

Keywords: experience of time, palliative care, transition, place of care, atmosphere, embodied, phenomenology.

INTRODUCTION

The multidimensional nature of time becomes apparent in suffering and when life is limited (1, 2). Cicely Saunders, the founder of the modern hospice movement, emphasizes that the limitation of time at the end of life can make this time one of the closest communications of a lifetime (3, p.105). The passage of time, time cycles, the trajectory of aging, transitions toward something, and life as a limited time is integral to human experience (3). According to Kant not only time but space is a prerequisite for all experience (4). The relationship between time, space and place are complex, multidimensional and interwoven. Nurminen emphasizes that time as a space of time refers to the cultural tradition in which man perceives time as something that goes beyond the world of physical reality (5) p.162. Lassenius stresses that space has an ontological meaning of to be a place of refuge from mental suffering as well as being simply a place to stay (1,p.252). According to Norberg-Schulz it is meaningless to imagine any happening in time without reference to a place (7). Place, body and time are necessary conditions for all experience, this relationship being so obvious that it is easy to ignore in health research (8-10).

In this study we describe the experience of time as it presents itself at different places when patients are living with severe illness and receiving palliative care. Experience of time as an important topic is under-researched and theoretically undervalued within nursing while environment is one of four major concepts of nursing (11). Place of care is an important part of care that needs attention especially in palliative care (12-16). Experience of time as it is perceived by patients at the place of care while receiving palliative care is of importance at a number of levels for the individual, the family and for health care policy (17-19).

BACKGROUND

Saunders emphasizes that palliative care is about helping the individual: “*to live until you die*” and that the quality of time is more important than its length (3), which implies to be in time at a place that supports and give space to live with a deteriorated body. Palliative care is an approach that improves the quality of life of patients and their families facing the problem(s) associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (20). Palliative care has made rapid progress from the early 1980s, but there is still a striking difference in practise across different countries and places (13, 21, 22). Overburdened and expensive hospital stays have resulted in health policy shifting attention from hospital to home care services as a means of meeting the complex medical needs at the end of life (23, 24). In Norway in 2011, 45.5% of deaths occurred in nursing homes, 34.1% in hospital and 14.2% in private homes (25). The reasons for the small number of home deaths are complex and often explained by a lack of resources, the level of safety required for patients and relatives, and the fear of unpredictable complications (17, 26), that may lead to frequent hospitalizations that are associated with the ever-changing, unpredictable situation at the end of life (27).

Theoretical perspective

This study is influenced by different descriptions of time, place, body and care grounded in phenomenology. Husserl, the founder of modern phenomenology has stated that the analysis of time-consciousness is the most important and most difficult in phenomenology (28). Heidegger adds a hermeneutical dimension to time by emphasizing that we always live in a context. While Husserl isolates time in relation to how it appears in our consciousness, Heidegger sees the experience of time in the relation to our “being in the world”. Being

cannot be separated from the world; being-in-the-world is time itself, stating that to dwell is a basic character of being. In the face of death the human being has the most extreme possibility to be confronted with itself (29-31). According to Norberg-Schulz dwelling implies something more than shelter; the spirit of a place has to be recognized as a concrete reality where a lifetime unfolds (7, 32). Bollnow stresses that in dwelling, man realizes his true essence. The house provides an inner space of shelter and privacy from an outer space of exposure and danger and roots the man firmly to the ground to avoid him being helplessly dragged away by the stream of time (33). Merleau-Ponty explicates how our human intentionality, our perception and experience of the world are embodied (34). The body is the vehicle of being, and having a body is to be involved in a definite environment. The ambiguity of being-in-the-world is translated by the body, and understood through time (35, 36). Nurse and philosopher Kari Martinsen (37), provides a valuable understanding of the importance of time and place in relation to care, dwelling, vulnerability, shamelessness, efficiency and throughput (38, 39). Today the hospital rooms are almost taken away from the patient because of efficiency, speed and throughput, and professionals must ask if they have time to share experiences and time to tell and to receive each other's stories in the hospital room (39). The place is a manifestation of the life-world and is life space in its presence (40). In health care there are rooms that shelter, where the patient is protected and keep their dignity and there is room that is shameful in its essence because the patient's vulnerability is exposed (41, p.186-7). She stresses that our relationship to time characterizes and "tunes" the place, distinguishing between two forms of bustle; being present busily occupied with helping the other in need, and being busily preoccupied doing tasks, which may lead to actually overlooking the other's existential suffering (40, 42-44).

Literature review

Literature was located in the databases PsycINFO, Medline, Pubmed and CHINAL by searching headings and abstracts with the following keywords: *Time, Patient, Environment, Surroundings or Place, Transition, Terminal care or Palliative care or End of life care, Phenomenology or Qualitative research*. There were no time restrictions on the search. In addition manual searches were performed searching reference lists of relevant books and articles. Previous research is divided into two categories:

1. Illness and experience of time.

As nurses and healthcare providers, we need to realize that although there may be equal time for everybody there are different perceptions of time, or temporality. Temporality could be seen as lived and subjective time as opposed to clock time or objective time (3). Illness represents not so much an isolated instant along a given time-line as a change which is embedded in the life narrative of the individual that must be considered against the horizons of past and future (45, 46). When it comes to severe illness it is vital to take into account the temporal structure (46, 47). Nurminen refers to patient`s stories to show how the shape of time alters through suffering and how the temporal movement creates a connecting movement that is enclosed and integrated into the human body (1). Living with severe incurable disease is associated with an on-going deterioration of the body and distressing symptoms that impact on the experience of time (1, 15, 48-53). Knowing that time is limited, but not how the disease will progress, is like stepping into an unpredictable space where the path forward is uncertain (54). Lassenius stresses that the space comes into view as a transit place in a person`s being where time can expand and diminish the space (6, p.250). During terminal illness there may be transitions between different clinical phases that can be hard to identify because of the unpredictability of the disease (55). Transition in palliative care is not only related to clinical phases but also to an uncertain time where mixed messages, poor communication, and

uncertainty can be manifested. However, the physical environment of the hospice can offer a place of ontological security allowing the uncertainty to be expressed (55, 56).

2. Illness, place of care and experience of time

The impact of the environment in palliative care is emphasized in the literature and documented in research (54, 57). According to Tunstall et al, a person is not an island - persons live their lives through places, and that is why the issue of place in healthcare should not be considered as a context, but within a context (10). Illness represents dis-ability to engage in the world in habitual ways, where the very nature of body as being-in-the world is transformed (45, 46). A threat to the body can incorporate a concurrent change where the surrounding world and environment take on a different character (45). Physical environment and people's relation to time are two interacting dimensions which combine to create the environment, giving the room a character and atmosphere. The character in the room and the environment created influence the atmosphere of in the caring encounters (1, 3, 54, 57-60). Home is reported to be a preferred place to be cared for when approaching death, even if the preference slightly weakens as death approaches (17, 19, 61). Illness in itself can be seen as being homeless-in-the-world, described as longing for a ground in a groundless world (50, 63, 64). However, there is a distinction between being at home and feeling at home (13, 14, 64). Home is not only located in space, it is also temporally structured. Home refers to the past and is often associated with one's provenance ("where you come from"). Home also refers to the future and to the final destination of existence. Feeling at home is described as an existential experience where people feel safe, and arguably this is the goal of effective palliative care (65).

STUDY AIM, DESIGN AND METHOD

The aim of this study is to describe the lived experience of time as given at different places (Table 1), when living with severe incurable illness and receiving palliative care.

The motivation for choosing a phenomenological design with open unstructured in-depth interviews as a method was that it afforded the opportunity to gather rich descriptions of time with variations and nuances (66, 67).

Sample and data collection

Data consists of 26 tape recorded interviews from 23 respondents, 9 men and 14 women, receiving palliative care in Norway. Three of the participants were interviewed twice because they wanted to talk more about the subject. All but one were diagnosed with severe incurable cancer, all but one lived at home and were either outpatients at a palliative day-care unit or had a temporary stay in a palliative care ward at a hospital or in a nursing home. The physical appearance of the disease varied; most respondents were very deeply marked by illness and mostly confined to their beds, while some were more able and mobile. The number of interviews conducted was determined by the amount and variation of information received. The interviews were carried out from April 2009 to February 2010.

Inclusion Criteria

The study participants were selected on the basis of the following inclusion criteria:

1. Having a severe incurable disease and receiving palliative care.
2. Over 18 years of age, male and female.
3. Having mental capacity.
4. Able to manage an interview.
5. Able to speak and understand Norwegian.
6. Representing different settings such as; palliative daycare units, palliative hospital bed units, palliative nursing home units, and private (own) homes.

Table 1 (see separate page)

Organizing the interviews

The nurse and the doctor in charge of the ward organized and selected respondents on the basis of the inclusion criteria, giving out written information and collecting informed consent. The first author was told when respondents had agreed to participate, and arranged directly with the participants a convenient time to conduct the interview.

Ethical issues

The study was approved by the Norwegian National Committee for Research Ethics, the Norwegian Social Science Data Service and the hospital administration. The study was conducted according to the guidelines issued by these institutions and to the Helsinki Declaration (68). Before the interviews, time was devoted to reflecting on the possibility that the research topic might be very sensitive, in light of which the interviews had to be conducted very carefully so as not to cause any emotional or psychological distress. In reality this concern did not manifest itself, as the respondents seemed to appreciate the opportunity to reflect and share their experience of place and time, especially if this could add to our knowledge and be useful for other patients.

The Interview

Face to face interviews were conducted in the respondent's own home or at different palliative care units at the hospital or in the nursing home. The respondents from the Palliative day-care unit were interviewed in a private room allocated for interviewing, while respondents at home were interviewed in their living room or in the patient's bedroom. Except for one interview, respondent and researcher were alone during the interview. After some

general words of introduction the purpose of the study and the issue of informed consent were repeated and confirmed. Demographic data such as gender, age and diagnosis were recorded. The research issue was raised in an open-ended question: *Can you tell me what you are thinking when you hear the word "time"*. The subsequent responses led to further questions about their experience of time at different places which the respondents had experienced during the course of disease, such as; home, hospital, nursing home or palliative care unit. A number of themes or prompts were used, such as; duration, rhythm, quantity and quality of time and the impact of time in connection with care, attitudes and progression of the disease experienced at different places. During the interviews it was important to be aware of and sensitive to the physical limitations of respondents, such as breathlessness when answering questions, and their ability to complete the interview.

Data analysis

The analysis performed was based on Amedeo Giorgi's descriptive phenomenological method (66, 69), which is an adaption of Husserl's phenomenological philosophy into a scientific method (70, 71). Descriptive phenomenology is intended to describe the experience as they are, without making causal explanations (34, 36). An important preparation when doing phenomenological research is to do a phenomenological reduction, which means to enclose one's pre-understanding of the phenomenon in parentheses and not to be too quick to make definite what is indefinite, allowing the phenomenon to be in its indefiniteness for as long as possible (72). According to Merleau-Ponty the best description of reduction is to adopt a wondering attitude to the phenomenon being explored; however, the most important lesson learned is the impossibility of a complete reduction (36, 72). The researchers, four nurses and a physician, all with varying clinical and research experience, which includes palliative care and different fields of research, have actively tried to be sensitive open and wondering during

the analysis to what is being conveyed through the interviews. The method is described in intertwined steps that vary from 3 to 5 in the literature (66, 69, 73). The analysis is not linear but a movement back and forth between these steps; they were modified and implemented as follows:

1. Interviews and literal transcriptions conducted by the first researcher, involving actively trying to be fully attentive, present and wondering to what presents itself.
2. Reading the literal transcriptions several times, trying to get a global sense of the whole through each interview.
3. Meaningful units that present themselves as related to the experience of time were separated and noted, revealing such areas as: *A changed life. A time of change. Being safe determines perception of time. Not knowing where to be.*
4. The data in the meaning units were organized and analyzed thematically using free imaginative variation to clarify what does not vary. The insight was expressed into disciplinary language, such as: *A bodily change also changes the perception of how it is to be at a place.*
5. Expressing the structure of the phenomenon:

The structure and diversity of each meaning unit were described in phrases such as: *Needing something to hold on to in an unpredictable time. A changed life is reflected in the experience of time.*

FINDINGS

What presented itself as distinct in terms of respondents' experience of time at the place was how the bodily condition of suffering, relief and increased deterioration was integrated in the experience of time; the experience of time at the place included the bodily condition of severe illness and the site's ability to protect, provide shelter and to immediately respond to painful and distressing symptoms. Based on the bodily changes due to the course of the disease the

experience of time was characterized by unpredictability and an ongoing transition to a changed space of life that is reflected in the experience of time and revealed in three different ways:

A transition from **a** predictable to **an** unpredictable **time**

Being struck by severe incurable disease marks a clear distinction between before and after.

Suddenly, the predictable time of everyday is changed to an unpredictable time of uncertainty, the patient no longer knowing where to be and what will happen next.

“I have no words for it, it's just so amazing how different everything has been since I became ill.” (P3).

Regardless of what happened, the time was described as a movement that varied in speed and quality ranging from fast to slow, and from being good to bad. To be embodied with severe illness had changed everything connected to a bodily change and this was reflected in the experience of time. If the change that happens is painful and difficult or frantic, the time can be described as terrible.

“It was so frantic all that happened the first six months that I have trouble remembering everything, but I do not care to remember it either because it was a terrible time (P14).

The bodily change caused by severe illness entails a transfer between different places within the health care system, with different space for self-expression, changing the everyday experience of time. In addition, the various places hold an atmosphere marked by time that affects the sense of dwelling in the place. Even though participants were grateful to be in a hospital when this was needed, the experience of the hospital as a busy place was prominent.

“In hospital time is busy. Health professionals are in a hurry, you can see it right away by the look in their eyes and everything. When I have been in hospital it has been for the fact that I have needed it. So then I'm grateful that I'm allowed to be there even if time passes more slowly” (P5).

Being in a busy place when embodied with severe illness the experience of time appears as a

paradox of being busy but going slowly, making the hospital safe but not a place for dwelling.

The bustling atmosphere leaves little room for self-expression when being weak and deteriorated, which can give a feeling of being ignored as a human being.

“I no longer bother to connect with them, because I know they have to “run” before you finish the sentence. It's gotten worse and worse, more and more patients, not more employees; they are “running” all day when they are at work. And it does not feel good for them, and it does not feel good for us” (P5).

When the situation is becoming more predictable, it is highly appreciated to come back home to an atmosphere of harmony and “everydayness”.

“When I'm home, I think time is like a gift. I do not know how to explain it otherwise; time is either tedious or short. If there would be something, it must be that there could have been more time, I tire faster, it is probably just the way it is, being seriously ill” (P5).

In an unpredictable time the trivialities of everyday life is what one longs for. Uniquely expressed by respondents in a despairing tone:

“So now I've just made it clear when I come home, we do not talk about disease whatsoever. It's not any discussion topic at all. We do like a normal family and shall live as normally as possible. And all agree on it, and we have talked a lot about death and all this, the children and all together. And all of them have accepted that this is how it is. But I think it's so terrible that they will see their father become weaker and weaker. You know he is not better, he just gets worse”(P3).

Time cannot be turned back; nothing is as before when one gradually grows weaker while becoming worse. Being in this time of unpredictability any new change can alter the experience of time at home from being a gift to a horrifying experience, which can lead to readmission, but this time to a palliative unit.

“Here at the Palliative Care department it is absolutely fantastic. When I came in here everything was hopeless, the pain overwhelmed me and I did not want to live any longer. Now I feel a new desire to live in the time I have left. I notice that I just lie in bed smiling to myself because it's so good to live without pain” (P5).

When pain is overwhelming, life is nothing but pain; to be relieved of overwhelming pain is to be given your life back as a new gift. The atmosphere appears more at ease in a palliative unit, which makes a difference to the experience of time.

“One day I was crying in bed, a nurse came in and just sat there until I had no more tears. It was of great importance to me. In this department (palliative care unit) employer has provided the opportunity for those working here to remain near the patient and this is hugely important and of immense impact. Elsewhere, they look at the clock all the time and are not present. They come in with painkillers and a glass of water and say drink this and then leave again” (P5).

There is something undefined about the staff’s relation to time in a palliative care unit, something that is reflected in their attitude or way of seeing, listening, in addition to know-how skills that permeate and tune the place that create a spirit of life and expand the space for living.

To be in transition from safe to unsafe time

When living in a condition of accelerating bodily weakness and unpredictable complaints, feeling safe and secure of obtaining help when needed are essential to how time is experienced.

“To be safe is what determines whether time feels good or bad, as it always has been. What I want for my time (here at the hospital) is to be safe and to have confidence that the health care system takes care of this last part of my life. Confidence is what it's all about in the days to come” (P5).

Even if the patient wants to be at home, the feeling of confidence is challenged at home.

Increased weakness and progression of bodily ailments can change the perception of home from a safe to an unsafe place to be.

“I am so short of breath. Now when I am dependent on oxygen and drugs, I feel unsafe at home. Home nurses come, but they leave again, and it will always take some time before they return. They are not there at the moment you really need them” (P2).

When living with a deteriorating body you are at the mercy of the place; in this situation, being at a safe place is revealed as essential for whether time feels good or bad. When insecurity becomes overwhelming, it is good to come to a place that can alleviate the suffering.

“I appreciate very much being here (in the palliative care unit). I will at least be here through next week. That I appreciate. For here we feel we know them in a way. It feels safer. So we

will spend time together this weekend, being together in a safe environment” (P2).

To be in a generous, safe environment makes it better to be together, but how to manage living when returning home remains a concern:

“Here and now I feel safe. So I have to exercise in order to I feel safe when I get home. If I'm unsafe when I come home, the joy of life disappears” (P5).

To feel unsafe gives an uneasiness and alertness that occupies the attention, while safety gives peace of mind and opens up opportunities to enjoy life and to participate in what is happening.

“It is only when I am confident that I have the opportunity to find and see the joys in life. It is these last pleasures I want. When I am safe my thoughts are free and I have the opportunity to find joy” (P5).

A transition from a homely to a homeless existence

Even though being safe is crucial to the quality of time, it can be difficult to find a safe place to be while living with severe illness. To feel unsafe at home and to be in an ongoing transfer between different places can give a sense of not fitting in any place (not belonging anywhere). To feel homeless when death is approaching might be like an existential cry of distress, which can make this vulnerable and limited time even more difficult.

“I'm not strong enough to be much alone. I need help; I need people around me who can help me when I need it. I just have to realize my situation. I cannot stay at home. They must find a place for me. I have to get to some place where I can stay” (P15).

When being weak and in need of much help the healthcare worker's emphasis on planning for transfer to another place or for a new discharge back home, is disturbing when death is close.

“Here at the palliative ward they want you to go home. Now everyone has to go home regardless of how sick you are. It is supposed to be no problem to be at home. They said that I could be in a hospital bed in the living room, but we do not want our home to be a hospital. I will not go home, and I have had to fight for my point of view against the health care system” (P2).

For those not able to stay at home for a variety of reasons, a nursing home may be the only option left.

“It looks like I must live in a nursing home, but I will not. I have no business being in a

nursing home. I wish there were a hospice near my home. And it seems necessary to me. They should go for it (find a hospice) instead of me being forced to end up in a nursing home where I do not fit in at all” (P3).

To be homeless when the body is strong is hard, but to feel homeless when the body is weak and one is facing dying, is to be in a situation where everything is unpredictable. To be in such a situation of homelessness can be characterized as a complete loss where the body fails, time is about to run out, and the very foothold in existence is being lost.

DISCUSSION

In this section, major findings will be discussed and interpreted referred to as an embodied, unique and subjective experience of time that originates from the passage of time.

This is an external condition common to all occurrences that bring continuous change in life.

Sometimes this change can be so drastic, such as being hit by a severe incurable illness marking a transition to a significantly changed life that is reflected in the experience of time.

Being in this transition two conditions stand out as essential for the quality of the experience of time: to feel safe or unsafe, and to feel at home or homeless (Figure 1). The discussion is based on a phenomenological understanding of being-in-the-world as time itself, where theoretical perspective and previous research are used to illuminate the findings.

It is challenging to distinguish between place, room and space when the words are homonyms, to clarify, we choose to use the word place about a physical location such as hospital, but let the word space remain ambiguous such as; something that goes beyond the physical reality (5) space for living, space for self-expression, space of refuge, the atmosphere between people or a fictitious space for thoughts, feelings and understanding (1, 6, 40, 42).

Figure 1 (insert figure 1)

Passage of time

Martinsen stresses that the passage of time runs independently of us, but affects us in different ways (42). Our respondents described the passage of time as a movement that was going on but at varying speed, such as going slow or fast. One can make sense of the variations in these experiences by including the body and place in the experience of time. The passage of time does not vary, it runs independently of us; what varies is the body and place (5, 42). Having a body is to be involved in a definite environment; however, what we are involved in varies and affects the quality of time (35, 36). According to Caldas & Bertero (2012) temporality is a central component of our experience of the world, offering an understanding of temporality as lived and subjective time as opposed to clock time or objective time (3). Temporality as lived embodied time can give a meaning to our respondent's statement of time going faster after being ill. Being in a situation where the lifetime is about to run out, the limited time left seems to pass faster (1). Heidegger stresses that being temporal is the fundamental assertion of being; to be confronted with one's own death reveals the true essence of being (31). This may be why Saunders characterizes this time as one of the closest communications of a lifetime (2).

Change

Without the passage of time, everything is like a fixed moment, just as in a picture or photograph where nothing moves and nothing changes. The subject in the picture is an illustration of life but is not life. To live is to be in a continuous change. The passage of time changes the body from childhood to old age, and moves us towards death. The passage of time appears as a contradiction that continuously repeats in a linear direction of no return (1). The repetition of day and season provides predictability in existence; gives us habits and traditions and opportunities to plan future activities by date and time and a feeling of an everyday that is recognizable and continuous, as this is how it tend to be (53). However, our

life is temporary and follows a linear one way direction of no return where nothing can be repeated (15, 42). Our lifetime is filled with unexpected changes, such as being struck by severe incurable disease, that incorporate a concurrent change where the surrounding world takes on a different character (1, 45, 46), such as the change of home from a safe to an unsafe place to live. Norberg-Schulz stresses that a place holds a fixed *structure* and a variable *atmosphere* as two different dimensions of the place that are necessary when describing its character (7, 32). The passage of time appears in the atmosphere of the place that varies throughout the day, as it also varies in accordance with our attitude, activity and relationship to time. The character of the place and our relation to time can make a place spacious or constrained for our expressions of life (39, 54, 60). Places can feel accommodating, generous, tolerant and life-confirming giving space for life, or restricted to self-expressions. Thus, being at a busy hospital might be felt more restricted to life expressions giving less space for life, while being at a palliative unit might be felt more generous. The place can feel accommodating, in harmony with time, where the expressions of life are seen, heard and responded to or constrained, in a hasty and busy time where the opportunity for expressions of life is limited and even overlooked or ignored (39, 40, 42). To be in a position where one did not have any tasks to do but plenty of time to observe, our respondents were very perceptive of the atmosphere at the place.

Transition

Sometimes the change can be so drastic, such as being hit by a severe incurable illness, that it marks a transition to a significantly changed life being reflected in the experience of time. Being in this transition two conditions stand out as essential for the quality of the experience of time: to feel safe or unsafe, and to feel at home or homeless. What revealed itself as distinct and significant for the experience of time is to be in a transition to a life of not knowing where to be and what next to happen. This is also confirmed by previous research in palliative care,

where transitions are related to an uncertain time and to physical changes that are hard to identify because of the complexity of the disease (1,45,46,57). To be embodied with severe illness can be compared to having a house in poor condition or, as our respondent said, “*the body is rotting away*”. When the walls are rotten, you will feel the draught from the outside; being weak and vulnerable you are more susceptible to the shifting environment outside. When a house is about to collapse, when a person is in transition to death, it becomes even more important to stand on solid ground to be able to find a space of refuge from embodied suffering (6, p.252, 33). However, to our respondents the ground felt changing and unsafe.

The experience of time at the place, when living with severe incurable disease

The main finding of this study is that experience of time is a unique experience, that it is characterized by an ongoing change sometimes so profound and that it marks a transition to an unpredictable space of time where the everyday experience is lost. However, the issue of being safe or unsafe and of feeling at home or homeless at the place being situated emerged to be of great importance to the quality of time at the end of life. In an unpredictable time period it becomes important to hold on to what is left of predictability in life. To our respondents it was important to be confident that the unpredictable embodied ailments were taken care of in a predictable manner. Feeling unsafe at the place in a time of unpredictability trapped and narrowed the space of mind in trying to cope with a changed life, while being safe at the place gave the patient predictability and enough space to live through the unpredictable time left.

Time unfolds in the room and is visible in concrete situations at the place. That's why the site's atmosphere and the body's condition are of importance for the experience of time, especially in palliative care when marked by serious illness. When time is limited, and the body is becoming deteriorated, weak and unpredictable, the ability of the place to predictably

shelter from the unpredictable is most important. However, it is the tuned atmosphere of foothold, belonging and security that makes one feel at home at the place that is one's dwelling (36, p.19). The ideal place for dwelling is at home, and this is also the goal of public health policy (18). However, if patients do not feel safe at home, for various reasons, they need a place where they can feel at home. According to Dekkers (63) the goal of palliative care, metaphorically speaking, is "the patient's coming home". However, for some of our respondents it was rather not having a home that was their greatest concern.

Limitations

The experience of time as it presents itself at different places when living with severe incurable disease and receiving palliative care is a fundamental, broad and ambiguous subject. The overall intention of this study is to describe aspects of this experience, within a phenomenological approach and perspective. What emerged as distinct in the face of the respondents and during the analysis was how the experience of time was connected to the total embodied circumstances of life which gradually led to a more interpretive approach that is reflected in the discussion. These modifications may have contributed to an awareness of the interconnectedness of the bodily condition and the place being situated on the experience of time. This study is limited, like any kind of research, by its theoretical perspective and its descriptive nature. However, phenomenological research has the potential to reveal basic phenomena of importance. The interviewer's skills and ability to interview respondents living with severe illness, as well as the interviewer's prior understanding, may have affected the nature of the questions that were asked and the way these topics were elaborated and analyzed. The literal transcriptions, the analysis of the material and the shaping of the manuscript were regularly discussed and reflected on within the research team.

Relevance to clinical practice

To help people with incurable severe disease to “live until they die” is to try to create some predictability and space for life in an otherwise unpredictable time. This implies equal awareness of body and place, when performing and facilitating palliative care, such as predictable treatment of unpredictable symptoms, a calm and comforting attitude in caring encounters, as well as predictability as regards the place to be, during the course of the disease. To be relieved of bodily complaints, be safe and comforted have a profound impact on the experience of time; however, where to be safe may change during an unpredictable time. This indicates a need to regularly and systematically include a question, whether the present place one is situated eases or imposes suffering, for example when using “The Edmonton Symptom Assessment System” (ESAS) (50). Great attention must be given to those who for various reasons feel unsafe at home, when they are in danger of feeling homeless not only at the place but also in existence.

CONCLUSION

The study shows that the lived experience of time as it presents itself at different places cannot be separated from bodily condition. In a situation of embodied suffering safety is revealed as the most important aspect of life, while a homely atmosphere is described as essential for feeling at home in existence. The place ability to shelter against bodily weakness and ailments, are essential to a person embodied with severe incurable disease, while the tuned atmosphere of the place is what makes life flourish or fade and shifting space for living. A homeless existence reaches its outer limits when the place of home no longer is a safe place to be. In this situation of vulnerability, it is essential that health care workers reinforce and enhance what is left of predictability by providing a safe, homely and predictable place to be and remain in peace. If they succeed in this, patients may have an opportunity to feel at home even when not being at home and to live securely until they die.

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Table 1

Participants	Number of respondents	Age	Total number of interviews	Interviewed second time	Interviewed in private(own) homes	Interviewed in Hospital Palliative Care ward	Interviewed in Hospital Palliative Day care ward	Interviewed in Palliative Nursing home
Female	14	42-88	16	2	3	5	5	3
Male	9	49-82	10	1		7	3	

Figure 1

The complexity of the experience of time when living with severe incurable disease

